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Patients and informal caregivers' experiences of burden of treatment in lung cancer and chronic obstructive pulmonary disease (COPD): a systematic review and synthesis of qualitative research

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ABSTRACT.

Objective:

To identify, characterise and explain common and specific features of the experience of treatment burden in relation to patients living with lung cancer or Chronic Obstructive Pulmonary Disease (COPD) and their informal caregivers.

Design:

Systematic review and synthesis of primary qualitative studies. Papers were analysed using constant comparison and directed qualitative content analysis.

Data sources:

CINAHL, EMBASE, MEDLINE, PsychINFO, Scopus and Web of Science searched from January 2006 to December 2015

Eligibility criteria for selecting studies:

Primary qualitative studies in English where participants were patients with lung cancer or COPD and/or their informal caregivers, aged >18 that contain descriptions of experiences of interacting with health or social care in Europe, North America and Australia.

Results:

We identified 127 articles with 1,769 patients and 491 informal caregivers. Patients, informal caregivers and healthcare professionals (HCPs) acknowledged lung cancer's existential threat. Managing treatment workload was a priority in this condition, characterised by a short illness trajectory. Treatment workload was generally well supported by an immediacy of access to healthcare systems and a clear treatment pathway. Conversely, patients, informal caregivers and HCPs typically did not recognise or understand COPD. Consequently, treatment workload was balanced with the demands of everyday life throughout a characteristically long illness trajectory. Treatment workload was complicated by difficulties of access to, and navigation of, healthcare systems, and a fragmented treatment pathway. In both conditions, patients' capacity to manage workload was enhanced by the support of family and friends, peers and HCPs and diminished by illness/smoking related stigma and social isolation.

Conclusion:

This synthesis has revealed significant differences in treatment workload between lung cancer and COPD. It has demonstrated the importance of the capacity that patients have to manage their workload in both conditions. This suggests a workload which exceeds capacity may be the primary driver of treatment burden.

Systematic review registration number:

PROSPERO CRD42016048191

Strengths and limitations of this study:

- To the best of our knowledge, this is the first systematic review and synthesis that compares treatment burden in malignant and non-malignant disease.
- The review synthesises patient and informal caregiver experience of treatment burden across a wide range of healthcare settings and systems
- The heterogeneity of studies included means uniformities highlighted should facilitate the development of an explanatory model of burden of treatment
- The data analysed, whilst ostensibly from primary sources, are seen through the multiplicity of theoretical lenses chosen by the studies' authors and their varying epistemological and ontological stances which may be a limitation of the study

Introduction:

Burden of treatment (BoT) is not simply the unavoidable workload that illness inevitably confers on patients and their informal caregivers but is a potentially *modifiable* workload which treatment for the illness may create (1). The literature on BoT discusses the concept of “capacity” and defines this as the resources and limitations that affect patients’ capability to carry out the work of chronic illness (1-3). Capacity may be viewed at an individual (i.e. the patient) or collective level (i.e. the patients’ social network) (4). Capacity may be affected by a range of variables, from socio-economic factors such as ethnicity and poverty, to the social skill necessary to engage and mobilize stakeholders (1-3, 5-12). A workload that exceeds capacity might, in some cases, be the primary driver of BoT for patients (1, 3). Neither workload nor capacity are static. They may fluctuate over time as illness progresses, functional capacity declines and patients’ social networks change (1-3) or, indeed, as the patient is able to accept, adapt and normalise their condition into their daily life (5, 9, 12, 13).

The literature (1, 7, 11, 14, 15) emphasises the importance of adequately equipping clinicians with tools to detect BoT and training in interventions that might ameliorate burden in order to provide “minimally disruptive medicine” (15). This is an approach to healthcare that takes into account patient priorities, multi-morbidity and seeks to reduce the BoT on the patient and informal caregiver (15).

COPD and lung cancer are the most common causes of respiratory-related mortality in the United Kingdom (UK), excluding pneumonia (16). Tobacco smoking is the main risk factor for both diseases, linked to an estimated 86% of lung cancer and

90% of COPD cases in the UK (17, 18). Thus, both may carry the stigma of a ‘self-inflicted’ disease (19, 20).

Tobacco is a legal drug, used commonly and has been previously socially acceptable. More recently, recognition of the significant risks of tobacco smoking and public health strategies to ‘de-normalise’ tobacco have contributed to a social transformation that actively stigmatizes smokers (21).

COPD generally has a protracted trajectory of increasing respiratory limitation, punctuated by recurrent episodes of worsening termed “exacerbations”. Globally, COPD is a major cause of chronic morbidity and mortality; prognosis is uncertain but many people die prematurely because of the disease or its complications (such as pneumonia) (22). Conversely, lung cancer typically has a rapid trajectory involving steady progression with a clear terminal phase (23). The prognosis for lung cancer is poor; only 1 in 10 patients in the UK live for more than 5 years after diagnosis. Lung cancer treatments in England are predominantly hospital-based: outpatient chemotherapy or systemic anti-cancer treatment or inpatient surgical treatment (24). In contrast, treatment for COPD generally involves self-management (management of treatment regimens by patients and informal caregivers in the home) (25). BoT may, therefore, be experienced very differently by patients living with these two common respiratory conditions.

Aim of the review:

We aimed to undertake a comprehensive search of international literature to identify, characterise and explain common and specific features in the experiences of treatment burden in relation to patients living with either lung cancer or COPD.

Research question:

What is burden of treatment in lung cancer and COPD and how is it experienced by patients and their informal caregivers?

Methods:

Identifying relevant studies

For this study we replicated and extended a previously developed search strategy which was built around three search concepts (26):

- (i) index conditions (heart failure, chronic kidney disease and COPD)
- (ii) qualitative research methodology terms
- (iii) patient/informal caregiver experience.

The search was piloted in MEDLINE and then adapted for other electronic databases used (CINAHL, Embase, Scopus, Web of Science, PsycInfo). We looked at primary qualitative studies examining patients with COPD and lung cancer and their informal caregivers' interactions with health and social care, rather than studies which explicitly examine treatment burden in COPD or lung cancer as there are so few. Searches were limited to countries with advanced healthcare systems comparable to the UK as the synthesis is intended to inform a future research project that will take place in the National Health Service (NHS) in England. We limited our search to publications from the year 2006 onwards. This is because, like Gallacher et al (7), we wanted to locate patient experiences of BoT in current rather than historical health and social care practices. Table 1 details inclusion/exclusion criteria.

Study selection and appraisal

KAL, MM, AC and JH individually screened citations and abstracts to assess eligibility against the inclusion/exclusion criteria. KAL, MM, AC, JH and CRM screened full text studies for eligibility. We used the RATS (relevance, appropriateness, transparency, soundness) framework to guide our decision making on inclusion (27).

Data extraction and analysis

KAL downloaded full-text articles into the qualitative data analysis software Nvivo 11, used to organise and manage data. KAL read the full text versions of identified papers to enable immersion in the data to understand their scope and context (28). KAL extracted text including verbatim quotes and authors' interpretative comments from the results and discussion sections of studies. Data were coded by KAL using a framework developed by CRM, AR, KAL, MM and AC, underpinned by robust, empirically derived, middle-range theories: BoT theory (1) and status passage theory (29). KAL, supported by CRM and AR, analysed data using directed qualitative content analysis (30) and constant comparison (31). Related codes were grouped in sets for each condition and comparing sets within and between conditions. Simple explanatory propositions were then formulated with which to characterise differences and similarities in treatment burden between conditions.

Results:

Characteristics of studies

Figure 1 shows each stage of the review process. We identified 127 articles: 85 COPD and 42 lung cancer. The papers included 1,233 COPD patients, 251 informal caregivers of COPD patients; 536 lung cancer patients and 240 informal caregivers

of lung cancer patients. The majority of the papers were set in the UK, USA, Canada and Sweden. Ninety nine papers used qualitative interviews, 14 used interviews alongside either participant observation or focus groups. Eleven studies employed focus groups, two studies used case study and one study used serial dialogue. Further characteristics of studies are available in Appendix 1.

Workload/capacity mismatch as primary driver of treatment burden

We took as our starting point Shippee et al's (3) proposition that a workload that exceeds capacity might be the primary driver of BoT. We grouped coded data into sets of **workload** (the affective, cognitive, informational, material and relational tasks delegated to patients/caregivers) and **capacity** (the affective, cognitive, informational, material and relational resources available to be mobilized by patients/caregivers).

Workload:

Diagnosis

For the majority of patients with COPD, the experience of receiving a diagnosis of COPD was not a memorable event (32-45) ; "a story without a beginning" (42). Often, patients had never received a formal diagnosis or were not informed of their diagnosis for many years. One study described how its participants questioned why they were recruited, unaware that they had been diagnosed with COPD (41). Even when given a diagnosis, many patients often did not understand the term 'COPD': "...as I say, I wasn't even sure, it had never been put to me, formally put to me that I'd got this obstructive pulmonary or whatever they call it" (34) (p.706).

In contrast, patients with lung cancer almost universally described the moment of diagnosis as a “shock” (46-52), an unexpected and undesirable “crisis” which “floods” patients’ lives (29). Patients felt overwhelmed by the existential threat of cancer that takes away their ability to plan for or even imagine a future (47, 53, 54).

Illness identity:

Several studies demonstrated a lack of public understanding of COPD (32-34, 36, 38, 41, 42, 44, 55-58). Thus, patients often had not heard of COPD prior to diagnosis and therefore had no expectations of the disease: “When cancer was excluded all worries about the future or fear of death fell away” (33) (p.558). Conversely, cancer has a recognisable public narrative, replacing tuberculosis as the disease the public most fears (59-62). In several of the studies, the patient’s experience reflected this narrative shift (49, 52, 63): “Patients acknowledged despair..and..hoped for an alternative diagnosis: “It doesn’t have to be lung cancer... it doesn’t have to be the worst”” (63) (p.1207).

Treatment: a priority for lung cancer

Consequently, treatment for the illness – often became the overriding priority in life for patients with lung cancer (63-66), suspending the demands of everyday life: “Life is immediately put on hold...so a normal everyday life didn’t concern me because everything revolved around treatment and only completion of the treatment was important so everything else didn’t matter” (65) (p.5).

COPD as a “way of life”

Conversely, patients often saw COPD as a “way of life” (42) not an illness. The management and treatment of ‘stable’ COPD symptoms was seen as something that has to be integrated into ‘everyday’ life rather than being a priority (34, 42, 56, 58,

67-72). Many patients with COPD, even with advanced illness, did not regard themselves as unwell (42, 58, 69, 70, 72). Patients reported exacerbations of COPD as 'proper' illnesses but saw the often debilitating symptoms of 'stable' COPD as a normal part of life, something to be accepted and coped with (69).

Identifying and accessing treatment options:

In the papers included, patients with lung cancer reported frequently having to make a decision about whether or not to have treatment, which they repeatedly phrased as a lack of choice: a choice between death or treatment (66, 73-76). Whilst ostensibly involved in the treatment decision-making process, some patients described having little real control over treatment options, believing they lacked the cognitive ability and specialist knowledge required to make informed treatment decisions (74, 75, 77):

Indeed, frequently patients described choosing to cede the cognitive burden of decision-making over treatment options to a trusted healthcare professional (HCP) (74-79).

For patients with COPD, identification of treatment options could, itself, be problematic (34, 56, 69, 80, 81). Patients described being repeatedly told that "nothing could be done for them" by HCPs in both primary and secondary care (34, 56, 69, 80, 81). Thus, papers reported patients identifying treatment options from other sources of information such as the experience of peers or through their own research (55, 56, 67, 80, 82). Once treatment options were identified, patients could experience difficulty in accessing treatments (33, 34, 38, 39, 41, 43-45, 57, 69, 72, 82-95):

Accessing and navigating healthcare

After diagnosis, patients with lung cancer frequently reported rapid access to healthcare institutions and specialist HCPs who recognise and understand lung cancer and co-ordinate its treatment workload. Furthermore, patients with lung cancer appeared to follow a relatively structured treatment pathway (48, 52, 65, 66, 76, 96-98). In contrast, patients with COPD described encounters with gatekeeping generalist HCPs who did not recognise or understand their disease (43, 44, 57, 80, 83, 86, 92, 93, 95, 99, 100) and, consequently, significant delays in accessing specialist care. Patients with COPD reported the hard work of accessing healthcare, having to navigate between healthcare providers, in a fragmented system, lacking a clear COPD treatment pathway (33, 36, 41, 43, 44, 57, 72, 82, 84, 86-88, 90-93, 95). Furthermore, patients described being expected to act as custodians of their own medical history, having to update HCPs with changes to their treatment (95, 101).

Practical workload:

Once treatment options were identified and accessed, patients with both conditions reported experiencing a significant practical workload, with multiple appointments for treatment, most commonly in hospitals for cancer (51, 73, 102) and occurring in a variety of settings for COPD (72, 81, 82, 84, 85, 101, 103, 104). Patients with both conditions described structural disadvantages such as the availability and cost of transportation and parking, physical restrictions in accessing healthcare (such as stairs), waiting for appointments and restricted time for appointments with HCPs that make their workload more onerous (33, 38, 41, 51, 57, 72, 73, 81, 82, 84-86, 93, 95, 102-104).

Patients with COPD and their informal caregivers reported being delegated a wide range of material treatment tasks by health care professionals to self-manage at

home. These included the management of complex medication regimens (32, 34, 41, 71, 90, 91, 93-95, 105-107); the operation of technologies such as oxygen (41, 44, 57, 58, 72, 82, 86, 88, 95, 107-117), nebulisers (32, 67, 86, 88, 105, 112) and non-invasive ventilation (68, 118). These also included self-management of the illness itself: avoiding exacerbation triggers, monitoring physical symptoms and help-seeking when appropriate (34, 36, 67, 71, 72, 87, 90, 91, 94, 101, 105, 119, 120). In contrast, patients with lung cancer described receiving highly specialised, predominantly hospital-based therapies with little delegation of few material treatment tasks (47, 49, 51, 52, 64-66, 73-78, 97, 121-123). The exception was a study interviewing patients receiving oral targeted therapies who described the rigorous process they underwent when securing and taking medication (124). This paper highlighted the priority patients with lung cancer gave to their treatment as they rigidly adhered to their delegated task (124).

In contrast, patients with COPD frequently used 'trial and error' to modify complex medication and treatment regimens to integrate with the workload of everyday life over their lengthy disease trajectory (41, 67, 87, 125, 126).

Attitude towards treatment:

Treatment as work:

In the papers included, patients often described COPD as a "planning" disease, balancing the work of everyday life with the material demands of managing their treatment workload (41, 71, 90, 91, 100, 106, 115, 127). This was complicated by the uncertainty of the illness trajectory making disease fluctuations difficult to anticipate and, consequently, to manage (32, 36, 38, 69, 105, 110, 128-130). Less commonly, patients with lung cancer also described the importance of planning and managing

their own treatment workload (46, 65, 66, 78, 96, 124). More commonly, patients with lung cancer were overwhelmed by the debilitating pathophysiological side effects of their treatment such as breathlessness, fatigue, nausea and vomiting and are unable to focus on anything apart from treatment completion (47, 54, 64-66, 73, 78, 122, 131-133):

Treatment as relief:

Patients with lung cancer often experienced the practical demands of treatment – the treatment workload – as a relief, despite potentially incapacitating pathophysiological side effects (50, 52, 75, 78). Patients repeatedly used the metaphor of treatment as “hope”, a lifebelt in the existential flood caused by the diagnosis of lung cancer (48, 50, 63, 73, 78, 124, 134, 135).

Some patients reported a sense of “limbo” once the practical workload of treatment has finished (47, 65, 74, 123, 136). This “limbo” was both existential (65, 123): “Now I have lived for something, to complete and survive the treatment and suddenly the priority of life is gone” (65) (p.5) or structural, where patients feel in transition between healthcare institutions (47, 74, 136).

Thus, paradoxically, patients with lung cancer could report a reluctance to stop treatment, despite its unpleasant pathophysiological side effects : “I’ll keep taking chemo as long as you’ll give it to me” (78) (p.105). Some patients with lung cancer also described continuing with treatment because they believed it is what their family wanted, rather than consulting their own preferences (66, 77, 124).

Patients with COPD reported how elements of treatment that support self-management (for example, educational sessions at pulmonary rehabilitation (PR)) provided a much needed sense of control over their condition (34, 71, 87, 100, 103,

116, 137-141). However, it was evident how fragile this sense of control might be, easily undermined by structural disadvantages such as transitions between healthcare institutions and lack of communication from HCPs (32, 36, 40, 57, 72, 82, 95):

“I said, put them bloody tablets back [after one of usual medications stopped in hospital, followed by him feeling unwell]. Don’t take stuff off me without telling me. And I swore at him, [hospital doctor] I did, I was blazing. For giving me a dodgy thing again. But that’s what you’ve got to put up with you see.” (40) (p.269)

This suggests unsupported and undermined self-management may be an exhausting and frightening, rather than, empowering experience for the patient and their informal caregiver. In the studies included, patients with COPD repeatedly describe the relief of respite from the demands of self-management that institutionally provided treatment (specifically hospitalization, PR, day hospice and specialist outpatient care) brings (56, 57, 80, 92, 95, 99, 120, 130, 139, 142-147):

“Sometimes you can think, when you’re too sick, that they [medical staff] can tell me what to do, so I don’t have to make all the decisions. I trust myself, but it would be nice if someone just took care of me like that.” (143) (p.1485)

However, particularly in the case of hospitalization, institutionally provided treatment may also significantly add to the workload of patients with COPD. Patients report a hospital stay as a chaotic, confusing and disruptive experience, with patients with COPD seen as “low priority” by the healthcare provider and frequently moved from ward to ward (40, 84, 92, 115).

Informational workload of treatment

Patients with both conditions describe being required to comprehend a large amount of information about their treatment (34, 36, 50, 55, 63, 65-67, 72, 74, 76, 77, 82, 87, 94, 96, 98, 101, 107, 110, 113, 122, 125, 131, 134, 136, 148-150). Commonly, patients with lung cancer felt that high quality information about their treatment was available to them when they required it (63, 66, 74-77, 96, 98, 123, 148, 149, 151). Nonetheless, the “shock” of diagnosis meant some patients struggled to retain or process information about treatment and therefore felt that further information was required once they began to assimilate their diagnosis (52).

Some patients with lung cancer wanted to be fully informed about their condition and treatment by their healthcare professional, including prognosis, however bleak this was (66, 76, 96, 98, 123, 148, 149). In contrast, other patients found being fully informed overwhelming and frightening, particularly when given comprehensive written materials (52, 74, 148). They wanted limited information from HCPs, appearing to use this as a coping strategy to maintain hope for as long as possible, (47, 50, 63, 65, 74, 76, 77, 79, 152, 153) preferring not to be “frightened with too much knowledge” (74) (p.969).

In a minority of cases, patients with lung cancer described information as not forthcoming when they wanted it and, as a consequence, felt ill-informed (77, 79, 134, 148). This was more frequently the case in patients with COPD. Patients often felt poorly informed about their condition and treatment at diagnosis and this continued throughout their disease trajectory (32-45, 81, 82, 88, 90, 91, 94, 100, 101, 108, 128, 154). This could be as fundamental as being given an inhaler without instructions on how to use it (41, 44).

Information could become a source of anxiety in both COPD and lung cancer when it was inconsistent or contradictory (35, 43, 55, 74, 79, 95, 115, 122, 123, 136, 142). Patients with lung cancer found the side effects of treatment, about which they had not been informed significantly, more distressing than those symptoms about which they had been warned and therefore anticipated (122, 131).

Capacity

Enhanced capacity following diagnosis:

Family and friends:

Patients with lung cancer and COPD repeatedly described family and friends as the main source of support for their treatment workload (36, 48, 54, 57, 65, 66, 72, 82, 85, 90, 91, 94, 98, 105, 115, 124, 148). Informal caregivers, like patients with lung cancer, prioritised the demands of treatment workload over the demands of everyday life and thus put their own life on hold:

Participants and carers described their ...life as inextricably tied to and affected by treatment patterns, appointments, complications and side effects. Additionally, the impact of various test results created a “scan by scan”, “treatment cycle by cycle” or “suspended” approach to life, which had an impact not only for the patient but also carers and family. (66) (p.24)

There could be an explicit recognition that this was possible owing to the short disease trajectory in lung cancer (53).

Informal caregivers’ participation in the treatment workload, whilst practically onerous, was often seen as an affirmation of the strength of their relationship with

the patient (54, 65, 98, 151). This was echoed in many of the COPD studies (35, 72, 94, 105, 115). Indeed, there was a suggestion from some informal caregivers that the demands of the caring role deepened and enhanced their relationship with the patient over the protracted COPD disease trajectory (57, 90). Yet, still more studies demonstrate that informal caregivers felt “compelled” to take on a caring role rather than this being a conscious choice. Their identity imperceptibly and inexorably shifts from family member to caregiver (35, 36, 90, 91, 94, 101, 105, 107). The length of the disease trajectory in COPD means that the informal caregiver, like the patient, has to balance the demands of treatment workload with the demands of everyday life (35, 90, 91, 94, 101, 107). The studies included repeatedly show that informal caregivers may find this practically limiting and affectively and cognitively demanding (35, 36, 68, 90, 91, 94, 101, 105, 107, 108, 110, 119).

Interestingly, despite the evidence of significant workload encountered by informal caregivers in COPD, it was patients with lung cancer who consistently described their fear of being a “burden” on their caregivers (48, 51, 53, 73, 77, 78, 96, 98, 135, 136, 148). This was less common in the COPD studies (41, 88, 103, 106), perhaps because the gradual development of the caring role over the long disease trajectory meant that the tasks the caregiver took on were not always obvious to the patient.

Health care professionals:

Patients with lung cancer frequently reported the importance of support from empathetic, trusted specialist HCPs in whom they have faith (48, 52, 65, 74-76, 78, 79, 96-98, 124). Patients with COPD also described positive experiences of interactions with HCPs (85, 93), particularly those with a specialist interest in COPD (56, 84, 87, 88, 95, 100, 105, 116) or those with whom they had relational continuity

(85, 93, 95, 105). Patients with COPD described lack of relational continuity with HCPs as making access to, and navigation of, the healthcare system more challenging (93, 95, 128, 143). In a small minority of lung cancer cases, patients had lost confidence in their HCPs (79, 96). This loss of confidence in HCPs appeared more common in COPD (34, 37, 40, 43, 44, 72, 80, 81, 86, 90, 91, 95, 106).

Peer support:

Patients with COPD appeared to benefit hugely from peer support (39, 67, 82, 129), which they generally accessed through PR (55, 56, 87, 103, 104, 137-141, 144, 155). Peer support had both psychosocial benefits as patients felt less isolated (55, 103, 104, 137-141, 144) and practical benefits as a means of information-sharing about treatment options (55, 56). In contrast, there appeared to be little formal peer support accessed by patients with lung cancer. Interactions with other patients tended to be impromptu and often transitory (73, 74, 156) perhaps because of the typically short disease trajectory of lung cancer.

Personal capacity to 'self-manage':

Patients with COPD described a process of getting to know their bodies and symptoms over their long disease trajectory and, through a process of trial and error, being able to adapt and normalise treatments into their daily life (34, 36, 41, 67, 72, 87, 120, 125). Patients attending PR reported the importance of support to self-manage, and education and information about their condition from specialist HCPs (87, 100, 103, 116, 138-140, 144). In contrast, patients with lung cancer described feeling ill-equipped to self-manage symptoms such as breathlessness at home, particularly in the earlier stages of treatment (133). This may be because the short disease trajectory of lung cancer does not allow patients to develop adequate self-

management techniques. Furthermore, patients do not have access to resources such as PR.

Diminished capacity following diagnosis:

Stigma:

Stigma occurs when society labels someone ‘tainted’ or ‘spoiled’ on the basis of an attribute that signals their difference to a societally perceived norm (157). Scambler (2008) usefully distinguishes between ‘enacted’ and ‘felt’ stigma (61). ‘Enacted’ stigma is actual discrimination by society against people with stigmatizing conditions. ‘Felt’ stigma is internalized stigma by people with stigmatizing conditions, manifesting itself as shame, guilt or blame or as fear of ‘enacted’ stigma.

In the papers included, patients with lung cancer and COPD frequently reported being considered culpable for their illness through smoking and consequently stigmatized by society (37, 39, 80, 86, 106, 151, 158). Patients with both conditions clearly internalized this stigma, repeatedly describing their diseases as “self-inflicted” (32, 34, 43, 96, 103, 106, 115, 127, 158-160). They experienced ‘felt’ stigma of self-blame, guilt and shame (37, 39, 43, 48, 96, 103, 106, 115, 119, 152, 158, 159).

Undeserving of treatment:

Some patients with COPD described how this internalized stigma led them to believe they do not deserve treatment (39, 103) : “I refused to go to the doctor. I thought it [COPD] was self-inflicted. If it’s self-inflicted, why bother anyone?” (103) (p.314). Conversely, in the papers included, patients with lung cancer did not describe themselves as undeserving of treatment. Only one patient in one lung cancer study

described having to “endure” the unpleasant side effects of treatment because of his smoking history (148).

Concealment of stigmatizing condition:

Both COPD and lung cancer are not immediately visible to others. Patients reported how fear of ‘enacted’ stigma led them to conceal their illness identity (37, 39, 48, 152). Thus, patients with both conditions attempted to impose a “closed awareness context” (29), concealing their illness from all but a select few.

Marked by treatment

Patients with both conditions also experienced the fear of ‘enacted’ stigma when ‘marked’ as unwell by their treatment (41, 73, 108, 117, 124). Hair loss caused by the side effects of lung cancer treatment is a clear signal of illness as is the ambulatory oxygen carried by some patients with COPD. In both conditions, therefore, the visible side effects of treatment or technologies may disrupt the “closed awareness context” patients have carefully maintained around their illness identity, leading to patients avoiding social situations and, consequently, social isolation.

‘Enacted’ stigma from health care professionals

Patients with COPD often described feeling stigmatized by their HCPs (38, 39, 43, 70, 86, 88-90, 106, 146). Patients with COPD and their informal caregivers felt that HCPs believed that patients who had smoked were not entitled to treatment or gave substandard treatment to (ex) smokers (38, 86, 89, 106):

“Well, the care from Father’s doctors was extremely basic and, I felt, on the most part extremely uncaring...The doctors really had an attitude of ‘You were a smoker, you’re dying of lung disease, and what do you want us to do about it” (35) (p.161).

Consequently, patients were reluctant to access treatment for fear of such enacted stigma (37, 39). Several papers reported the difficulties of accessing treatment for patients who had smoked (35, 86, 89, 106). One study described an extreme example of healthcare professional stigma where the authors argue that patients receiving non-invasive ventilation, an unpleasant treatment for exacerbations of COPD experienced this as a “punishment” for their “self-inflicted” disease (146).

In contrast, in the studies included, patients with lung cancer did not describe encountering stigmatizing attitudes from HCPs. Only one patient in one study was concerned that their care would be affected because of the links the disease had to smoking (158).

Social isolation:
Self imposed:

Frequently, patients with lung cancer and COPD experienced social isolation because of their illness (35, 36, 41, 52, 65, 86, 88, 90, 91, 100, 101, 103, 105, 107, 111, 115, 117, 119, 120, 127, 129, 136, 138, 143, 156, 161, 162). This might be self-imposed because of embarrassment about visible symptoms (such as breathlessness and cough), medications (such as inhalers) or health technologies (such as oxygen) that mark patients as ill and therefore expose them to the threat of enacted stigma (41, 73, 108, 114, 117, 124, 127, 132). In the papers included, social isolation was also a result of common psychological comorbidities such as

depression, low mood and anxiety following diagnosis leading to avoidance of social situations (52, 100, 103, 115, 129, 138, 156). Additionally, in COPD, self-imposed isolation was also used as a self-management technique to avoid exacerbation triggers (such as the risk of infection from crowds) (91, 143).

Involuntary:

Social isolation might likewise be involuntary in both lung cancer and COPD as friends withdrew and social networks contracted (49, 52, 103, 107, 117, 129, 156). Patients reported feeling “contagious” (49)(p.734), (107)(p. 145)

Patients with COPD reported that the practical and logistical challenges of the treatment workload itself (for example, the weight of portable oxygen cylinders, the fear of running out of oxygen while waiting for appointments, having complex technologies such as non-invasive ventilation at home) further added to involuntary social isolation (37, 41, 57, 58, 68, 72, 82, 86, 108, 111-113, 115, 117, 143).

For patients with COPD, involuntary social isolation appeared to worsen with disease progression and the consequent relentless deterioration of physical function (36, 88, 90, 105, 111, 129, 136, 161, 162). In the papers included, there were fewer accounts of this from patients with lung cancer, perhaps because of the typically short disease trajectory (136). In COPD, involuntary social isolation clearly extended beyond the patient to affect the informal caregiver as their responsibilities increased with the pathophysiological decline of the patient (35, 36, 90, 91, 101, 105, 107).

Discussion:

Strengths and limitations:

This systematic review and qualitative synthesis differs from previous reviews on BoT. BoT has been examined generally across all conditions (5, 12), with capacity

considered specifically (2). Other systematic reviews are condition specific: heart failure (8, 10) and stroke (9). Yet more consider treatment burden in multiple chronic conditions: diabetes, chronic kidney disease and heart failure (6) and chronic kidney disease, heart failure and COPD (163). This review, like May et al (2016), considers patient and caregiver interactions with health care services in order to characterise treatment burden but identifies primary qualitative papers rather than systematic reviews and meta-syntheses.

To the best of our knowledge, this review is the first to explicitly compare BoT in malignant and non-malignant disease. As such, it offers a novel review which synthesises patient and informal caregiver perspectives on burden of treatment in malignant and non-malignant disease across a range of healthcare systems and settings. It identifies and characterises BoT in lung cancer and COPD through the development of a taxonomy (Table 2). This has important implications both for researchers seeking to understand BoT and for clinicians, as they seek to ameliorate the impact of treatment on respiratory patients and their informal caregivers.

The heterogeneity of the papers included is both a strength and limitation of this synthesis. The heterogeneity of papers means uniformities identified through the taxonomy should facilitate the development of an explanatory model of burden of treatment (164). However, the taxonomy has been developed from descriptions of patient experience taken *out of context*. It describes the generalities of patient experience across multiple healthcare systems and settings, rather than considering factors such as socioeconomic status and the attributes of healthcare systems that have been shown to be important in the consideration of BoT (1). Furthermore, qualitative research is, necessarily, interpretative and therefore the data analysed, whilst ostensibly from primary sources, are seen through the multiplicity of theoretical

lenses chosen by the studies' authors and their varying epistemological and ontological stances.

What is not in the literature

The studies identified focus almost exclusively on the index conditions of lung cancer and COPD. They do not discuss the issue of multi-morbidity which may have a significant impact on BoT (3).

Illness as agent; patient as agent:

The overriding discourse evident throughout the lung cancer studies is that of 'illness as agent'. Patients with lung cancer, informal caregivers and HCPs immediately recognise lung cancer as an existential threat. In order to stave off death, the significant demands of treatment workload become the overriding life priority in what is typically a short illness trajectory. Patients with lung cancer have to undergo a gruelling treatment workload in secondary care, with potentially debilitating pathophysiological side effects but limited delegated tasks from HCPs. This workload is generally well supported by an immediacy of access to healthcare institutions and specialist HCPs and a typically clear and structured treatment pathway. Patients with lung cancer often regard the practicalities of the treatment workload as a relief from the cognitive burden the existential threat of their illness identity has imposed. Patients and informal caregivers use the simile of "treatment as hope" and are reluctant to stop treatment, despite devastating side effects.

Conversely, the recurrent theme throughout the COPD studies is that of 'patient as agent'. Patients do not recognise or understand their illness and therefore do not consider it a terminal disease. Consequently, the demands of treatment workload are balanced with the domestic, professional and sentimental demands of the workload

of everyday life throughout the typically long illness trajectory. Patients with COPD are delegated a wide range of highly complex treatment tasks by HCPs to self-manage at home. This workload may be made more onerous by difficulties of access to, and navigation of, healthcare systems, generalist professional gatekeepers who lack understanding of COPD and a fragmented treatment pathway that does not meet the needs of home-based self-management. Synthesis of patient and informal caregiver accounts demonstrates that poorly supported self-management is hard, unrelenting work for patients with COPD and their informal caregivers. Patients and their informal caregivers can build up strategies over time to self-manage their condition more effectively, particularly when supported by healthcare provision such as PR. Nonetheless, pathophysiological deterioration and increasingly complex management and treatment regimens mean that the demands of the treatment workload over the long disease trajectory accumulate. Thus, institutionalized care that temporarily relieves patients and informal caregivers of the practical, affective and cognitive workload of self-management may be seen as a welcome respite from self-management.

Social skill, capital and structural resilience

Patients with lung cancer and COPD are typically able to draw on the support of family and friends which enhances their social skill (the extent to which they are able to secure the co-operation and co-ordination of others) and social capital (their ability to access informational and material resources), bolstering their structural resilience (their potential to absorb adversity) (1). Like patients themselves, informal caregivers of patients with lung cancer recognise cancer’s existential threat and prioritise supporting the treatment workload over the demands of everyday life. This support can be a cathartic and life-enhancing process for patients and informal caregivers

alike. While this can also apply in COPD, informal caregivers often lack choice in taking on the care-giving role, describing an inexorable process of accumulating responsibility over the long disease trajectory as patients' functional performance deteriorates.

The "weaker ties" (165) of peer support are extremely important in enhancing the social skill and capital of patients with COPD and bolstering structural resilience. In lung cancer, because of its high mortality and short disease trajectory, patients are less likely to mobilise peer support, as their peers die around them.

Illness related and especially smoking related 'felt' and 'enacted' stigma degrade the social skill and capital of patients with both conditions. The invisibility of both conditions, unless 'marked' by treatment means that patients may attempt to conceal their condition, leading to social isolation. Social isolation is increased by the psychosocial impact of diagnosis and pathophysiological deterioration caused by both illness and the side effects of treatments. Stigma and social isolation and the consequent attrition of social skill and capital reduces the structural resilience of patients with both conditions.

Conclusions:

This qualitative synthesis of lung cancer and COPD papers demonstrates that the workload of treatment may be very different in each condition. The socio-cultural status of cancer as the most dreaded of all diseases means that 'illness is agent'. Thus, lung cancer patients are required to subordinate the demands of everyday life to the demands of the treatment workload. Patients have little choice but to follow a structured treatment pathway, in healthcare systems that generally meet the needs of their typically short diseases trajectory. Conversely, in COPD, patients are

1
2
3 expected to exert agency over their own condition, “empowered” to self-manage,
4
5 integrating the demands of the treatment workload into their everyday life. Patients
6
7 have to identify their own treatment pathway, navigating between institutions, in
8
9 healthcare systems that are not set up to meet the needs of their uncertain and often
10
11 lengthy disease trajectory. The differences in the treatment workload of lung cancer
12
13 and COPD identified by this synthesis resonate with other qualitative studies
14
15 comparing cancer with other chronic conditions (predominantly heart failure but also
16
17 COPD and motor neurone disease) (166-168).
18

19
20
21 Despite the differences of the treatment workload between conditions, this meta-
22
23 synthesis has demonstrated the importance of the personal and collective capacity
24
25 available to patients and their informal caregivers in both conditions, suggesting that
26
27 a workload which exceeds capacity is likely to be the primary driver of treatment
28
29 burden.
30

31
32 **Twitter:** Follow Kate Lippiett @katelippiett and Carl May @CarlRMay
33

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45
46 the conceptual framework informing this study. KAL designed the review with
47
48 assistance from CRM and AR. KAL and CRM assisted by AC, MM and JH (non
49
50 contributing author) undertook literature searches. KAL assisted by AC, MM, JH (non
51
52 contributing author) and CRM screened titles, abstracts and full papers. KAL, CRM,
53
54 AC, and MM developed an initial coding frame for qualitative studies of Burden of
55
56

Treatment. KAL performed first-line content analysis and constant comparison. CRM and AR critically reviewed the manuscript for important intellectual content; all authors approved the final version of the paper. KAL is guarantor.

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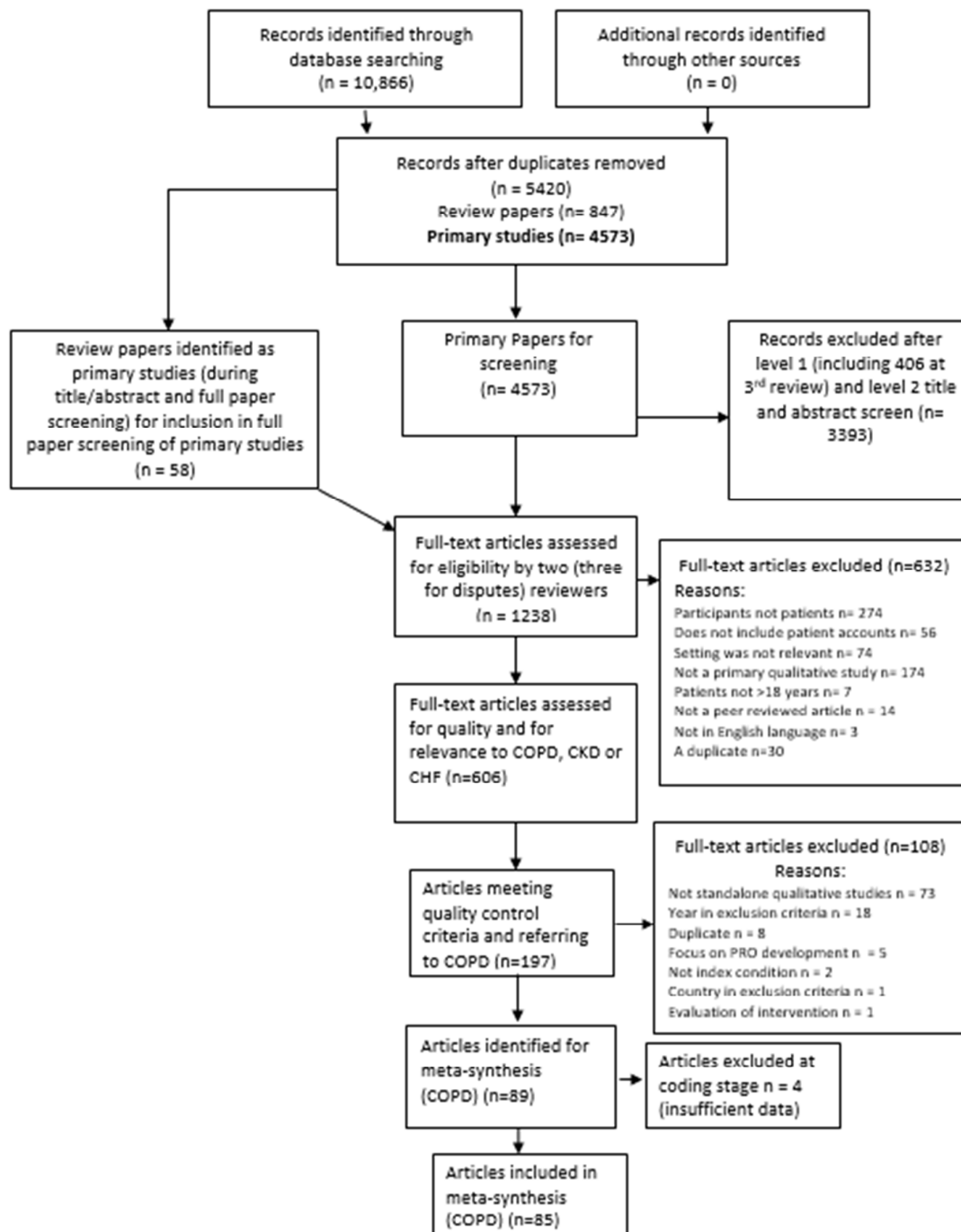
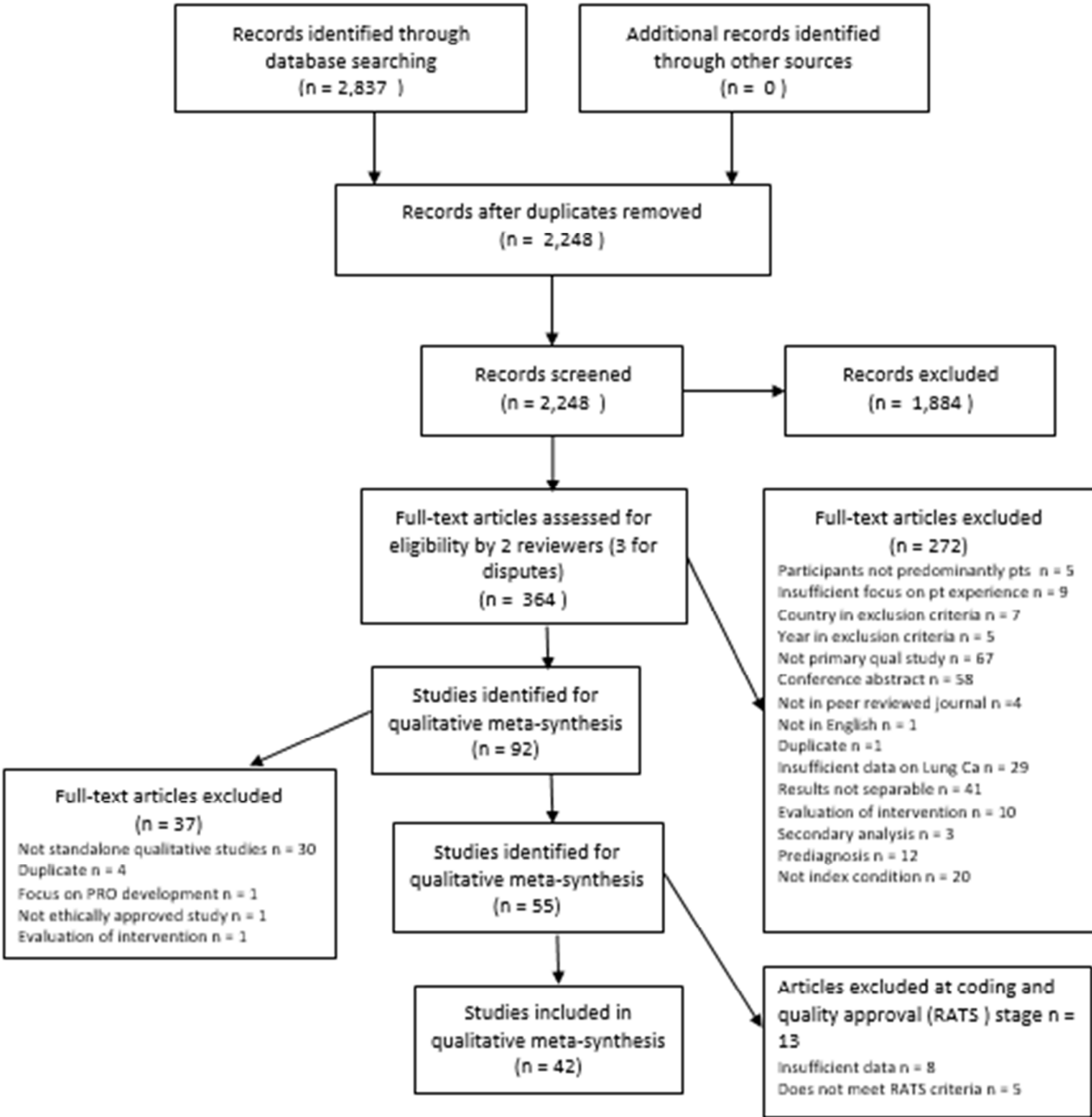


Figure 1a

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For more information, visit www.prisma-statement.org.

Figure 1b

Table 1

Inclusion criteria	Exclusion criteria
Participants: aged >18, diagnosed with lung cancer or COPD, or their informal caregivers	Reports: of treatment effectiveness, for example RCTs; reports of healthcare provision which are not focused on patients' or informal caregivers' experiences; qualitative studies which focus only on professional experience, or report secondary analyses, or review or synthesise data; editorials, notes, letters and case reports; protocols of qualitative studies, mixed methods studies
Reports: results of primary qualitative studies of patients' or informal caregivers' experiences of interactions with health and social care services published in peer reviewed journals	Insufficient data to answer research question
Settings: healthcare systems in Europe (excluding Turkey), North America and Australasia	
Date of publication: between 1 January 2006 and 31 December 2015	
Language: English	

Table 2. Taxonomy of treatment burden in lung cancer and COPD.

PRIMARY CONSTRUCT	SECONDARY CONSTRUCT	LUNG CANCER	COPD
Workload	Diagnosis /illness identity	Diagnosis as shock	Diagnosis imperceptible
		Obvious illness identity with socio-cultural resonance (therefore understood by patient/informal caregiver/healthcare professional)	Unclear illness identity, without socio-cultural resonance (therefore poorly understood by patient/informal caregiver/healthcare professional)
		Short disease trajectory (clear to patient and informal caregiver)	Long and uncertain disease trajectory (unclear to patient and informal caregiver)
	Treatment options	Lack of options: treatment or death	Lack of treatment options (lack of information or feeling that 'nothing can be done' from health care professionals)
		Treatment: decision to cede control over choice of treatment options to trusted healthcare professionals	
		Negative cases (less common): take control of treatment workload	
	Access to/navigation of healthcare system/ Institutions	Immediacy of access to healthcare	Difficulties with access to healthcare
		Specialist health care professionals with specific knowledge of lung cancer	Generalist health care professionals who lack specific knowledge of COPD
		Structured treatment pathway	Fragmented treatment pathway
		Sense of 'limbo' once treatment finished	Patient/informal caregiver acts as navigator between healthcare institutions and conduit of information
	Practical workload of treatment	Specialist treatment workload in secondary care with debilitating pathophysiological side effects	Multiple appointments for treatment in primary, secondary care and in the community
		Limited delegated tasks from healthcare professionals	Significant workload of delegated treatment tasks at home from healthcare professionals
		Lack of ability to self-manage unanticipated or novel symptoms	Ability to self-manage symptoms developed over time through trial and error
	Informational workload of treatment	Generally high quality information provided in written form and from	Patients typically poorly informed about condition from diagnosis to death

		specialist health care professionals	adding to treatment workload
		Lack of information as a deliberate choice on the part of patients – a tactic for maintaining hope in the face of a poor prognosis	Conflicting/contradictory information adds to patient/informal caregiver distress
		Conflicting/contradictory information adds to patient/informal caregiver distress	
	Attitude towards treatment	Demands of treatment workload as overriding life priority (for both patient and informal caregiver)	Demands of treatment workload have to be balanced with domestic/professional/sentimental demands of everyday life (for both patient and informal caregiver)
		Practical demands of treatment workload as a relief from the existential threat of cancer	Practical demands of treatment workload as hard work
		Treatment as hope	Institutionalized care as respite from unrelenting demands of self-management
		Reluctance to stop treatment despite debilitating pathophysiological side effects	
		Treatment for family rather than for patient	
	Capacity (Enhanced by diagnosis)	Family and friends	Family and friends are seen as the main source of support post diagnosis (but fear of being a 'burden' on family)
			Family and friends are seen as the main source of support post diagnosis
		Family and friends are able to prioritise supporting the patient through their treatment workload owing to the short disease trajectory and the recognition of the patient's likely imminent death	Family and friends have to balance the demands of the treatment workload with the demands of everyday life owing to the long and uncertain disease trajectory
		Support for the patient's treatment workload seen as an affirmation of the strength of the patient/family member relationship in the face of imminent death	Support for the patient's treatment workload may be seen as an affirmation of the strength of the patient/family member relationship
			Caregivers feel compelled to take on a care-giving

			role over the long duration of the disease trajectory
	Healthcare professionals	Importance of support from empathetic, trusted healthcare professionals in whom patients have faith	Importance of support from trusted healthcare professionals, especially those with specialist knowledge of COPD
		Negative cases (less common): loss of faith in healthcare professionals	Importance of relational continuity with healthcare professionals making access to and navigation of the healthcare system and its institutions easier
	Peer support	Little peer support available for patients with lung cancer. What is available appears impromptu and transitory	Loss of faith in healthcare professionals
			Peer support is an important resource and is generally accessed through pulmonary rehabilitation
			Shared experiences with peers reduces isolation
			Peer support is used as a resource for information sharing
Capacity (Diminished by diagnosis)	Stigma	Disease trajectory	Patients feel ill-equipped to self-manage unfamiliar symptoms at home
			Patients get to know their bodies over many years, adapting and normalising their treatment into everyday life
			Patients are considered culpable for their illness and stigmatized by society
			Patients are considered culpable for their illness and stigmatized by society
			Patients consider themselves culpable for their illness: a “self-inflicted” disease
			Patients consider themselves culpable for their illness: a “self-inflicted” disease
			Patients experience ‘felt’ stigma of blame, guilt and shame
			Patients experience ‘felt’ stigma of blame, guilt and shame
			Patients attempt to conceal their condition owing to fear of ‘enacted’ stigma leading to social isolation
			Patients attempt to conceal their condition owing to fear of ‘enacted’ stigma leading to social isolation
			Patients feel ‘marked’ by visible treatment leading to social isolation
			Patients feel ‘marked’ by visible treatment leading to social isolation
			Patients internalize stigma, considering themselves undeserving of treatment
			Patients experience

			'enacted' stigma from healthcare professionals, making access to treatment challenging
	Social isolation (Self-imposed)	Embarrassment about symptoms, medications and treatment technologies which mark the patient as ill leading to fear of 'enacted' stigma	Embarrassment about symptoms, medications and treatment technologies which mark the patient as ill leading to fear of 'enacted' stigma
		Psychological co-morbidities lead to avoidance of social situations	Psychological co-morbidities lead to avoidance of social situations
		Social awkwardness – fear of avoidance/discussion of condition and treatment	Social awkwardness – fear of avoidance/discussion of condition and treatment
			Exacerbation triggers – leads to avoidance of social situations
	Social isolation (Involuntary)	Illness as contagious: social networks contract as friends withdraw	Illness as contagious: social networks contract as friends withdraw. Isolation worsens with disease progression and deterioration of physical function
			Logistical difficulties of treatment workload limits patient to home
			Extends beyond patient to affect informal caregiver

Study	Year	Country	Qualitative method	Index condition	Setting	How sampled?	Sample	Age of sample	Gender of sample	How data analysed?	Study details
Adams et al #157	2006	UK, Netherlands, Denmark	Interviews	COPD	Community	Convenience	23 patients	38-84	16M, 7F	Descriptive (thematic analysis)	To explore the notion of COPD exacerbations from the viewpoint of patients who had recently suffered an exacerbation.
Arnold, E. #165	2011	UK	Interviews	COPD	Community	Purposive	27 patients	54-85	14M, 13F	Theory building (grounded theory)	To obtain in-depth information about perceptions and use of prescribed ambulatory oxygen systems from patients with COPD to inform ambulatory oxygen design, prescription and management.
Arnold, E. #166	2006	UK	Interviews	COPD	Pulmonary rehabilitation (hospital based)	Participants screened against eligibility criteria. All eligible patients invited to participate. Participants recruited until no new themes emerged.	20 patients	45-85	9M, 11F	Theory building (grounded theory)	To explore the experiences of COPD patients invited to join a pulmonary rehabilitation programme.
Boyle, Anne H #9	2009	USA	Interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	10 wives	57-71	10F	Theory informed (phenomenological-hermeneutic approach)	To describe and understand the meaning of the experience of living with a spouse who has COPD
Caress, A.#170	2010	UK	Interviews	COPD	Acute hospital	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	14 patients, 12 family members	Patients = 60-80. Family members not stated	Patients = 8M, 6F. Family members = 3M, 9F	Descriptive (content analysis)	To generate in-depth insights into patients' and family members' understanding of the causation, progression and prevention of COPD and the role of health promotion with this population.
Clancy, Karen #13	2009	UK	Serial interviews	COPD	Acute hospital	Participants screened against eligibility criteria. Those eligible who agreed to participate included. Informal care-givers nominated by patients.	9 patients, 7 care-givers	Patients = 57-78. Care-givers = 50-78	Patients = 6M, 3F. Care-givers = 2M, 5F	Theory informed (phenomenological-hermeneutic approach)	To explore the existential experiences of patients with COPD who had been prescribed long-term oxygen therapy and their carers
Clarke, A.#14	2010	UK	Interviews	COPD	Community	Purposive (maximum variation)	23 patients	50-80	14M, 9F	Theory building (grounded theory)	To explore patients' views of an early supported discharge service for COPD
Cooke, M.#15	2012	UK	Focus groups	COPD	Community	Purposive	8 HCPs, 30 patients, 2 care-givers	Patients = 48-73. Care-givers and HCPs not stated	Patients = 16M, 15F. Care-givers = 2F. HCPs not stated	Descriptive (thematic analysis)	To define, compare and order 'assessed needs and defined outcomes' of professional providers of COPD services with patients' prioritised needs and defined outcomes' and relate these to service provision
Curry, R. #172	2006	UK	Interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	11 patients	Not stated	Not stated	Descriptive (thematic framework approach)	To explore patients' views of introduction of a new nurse-led urgent care team (UCT) for patients with COPD
Dickenson, J.#19	2009	UK	Interviews	COPD	Community	Participants screened against eligibility criteria.	12 patients	Not stated	Not stated	Descriptive (framework approach)	To explore the COPD patient's perception of their dietary habits and nutritional status and to identify their perceptions of dietary health and its impact on general quality of life.
Ehrlich, Carolyn #22	2010	Australia	Interviews	COPD	Community	Theoretical sampling	9 patients	56-77	4M, 5F	Theory building (grounded theory)	To report how people with COPD gather, interpret and apply health affecting information
Ek, K.#23	2014	Sweden	Interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible, who agreed to participate included.	13 family members	Not stated	7M, 6F	Descriptive (content analysis)	To retrospectively describe the final year of life for patients with advanced COPD with a focus on death and dying from the perspective of relatives.
Ek, K.#24	2011	Sweden	Serial interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	4 patients	66-75	1M, 3F	Theory informed (phenomenological-hermeneutic approach)	To describe the experience of living with advanced COPD and long-term oxygen therapy when living alone
Ek, K.#25	2008	Sweden	Interviews	COPD	Hospital	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	8 patients	48-79	3M, 5F	Theory informed (phenomenological approach)	To describe the essential structure of the lived experience of living with severe COPD during the palliative phase of the disease
Ek, K.#26	2011	Sweden	Serial interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	4 couples (4 patients, 4 spouses)	67-74	4M, 4F	Theory informed (phenomenological-hermeneutic approach)	To examine couples' experiences of living together when one partner has advanced COPD
Ellison, L. #27	2012	UK	Interviews	COPD	Community	Convenience and purposive	14 patients	49-79	7M, 7F	Descriptive (constant comparison and framework approach)	To understand the mental health needs of people living with COPD
Fischer, M. J. #31	2007	Netherlands	Interviews	COPD	Pulmonary rehabilitation (outpatient)	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	12 patients	34-77	8M, 4F	Theory informed (interpretative phenomenological analysis)	To examine patients' pretreatment beliefs and goals regarding pulmonary rehabilitation
Fraser, D. D.#34	2006	USA	Interviews	COPD	Community	Purposive	10 patients	59-86	5M, 5F	Theory informed (phenomenological-hermeneutic approach)	To understand how COPD affects the lives of patients.
Gale, N. K.#36	2015	UK	Interviews	COPD	Community	Purposive	20 patients, 4 carers, 15 HCPs	Patients = 52-83. Carers not stated, HCPs = 26-54	Patients = M = 8, F = 12. Carers and HCPs not stated.	Theory building (grounded theory)	To explore experiences of domiciliary non-invasive ventilation in COPD, to understand decision-making processes and improve future palliative care
Goodridge, D.#41	2011	Canada	Interviews	COPD and bronchiectasis	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	7 patients	57-88	2M, 5F	Descriptive (interpretive description)	To explore the impact of living with advanced chronic respiratory illness in a rural area
Gullick, J.#45	2008	Australia	Serial Interviews	COPD	Community	Convenience	15 patients, 14 family members	Patients = 55-77. Family members = 29-82	Patients = 9M, 6F. Family members not stated	Theory informed (phenomenological-hermeneutic approach)	To explore the experience of the person who lives within a body with COPD
Guo, S.E. #161	2014	Canada	Interviews and focus groups	COPD	Pulmonary rehabilitation (outpatient)	Patients screened against eligibility criteria. Those eligible who agreed to participate included. HCPs sampled purposively.	25 patients, 7 HCPs	Patients = 53-84. HCPs not stated.	Patients = 13M, 12F. HCPs not stated.	Descriptive (thematic analysis)	To describe the experiences of patients who are in a pulmonary rehabilitation (PR) programme and explore the perceptions of patients and HCPs about what improves effective PR
Gysels #48	2008	UK	Interviews and participant observation	COPD	Community and outpatient clinics	Purposive	18 patients	52-78	7M, 11F	Theory building (grounded theory)	To explore the experience of breathlessness in patients with COPD through patients' accounts of their interactions with services
Gysels #178	2010	UK	Interviews and participant observation	COPD	Community and outpatient clinics	Purposive	18 patients	Median 69/70	7M, 11F	Descriptive (narrative analysis)	To investigate how the experience of breathlessness in COPD influences patients' attitudes toward the end of life and their quality of life
Habraken #49	2008	Netherlands	Interviews	COPD	Outpatient clinics and respiratory centre	Purposive	11 patients	61-83	8M, 3F	Descriptive (thematic analysis)	To gain insight into why patients with end-stage COPD tend not to express a wish for help
Halding #50	2012	Norway	Serial interviews	COPD	Pulmonary rehabilitation (outpatient)	Purposive (maximum variation)	18 patients	52-81	13M, 5F	Descriptive (thematic analysis)	To explore the experience of patients with COPD in terms of their transitions in health during and after pulmonary rehabilitation
Hall #53	2010	Canada	Interviews	COPD	Acute hospital	Patients screened against eligibility criteria.	6 patients	Mean age 69	4M, 2F	Descriptive (exploratory descriptive)	To describe the perceptions of people living with severe COPD with respect to the end of life
Harris #55	2008	UK	Interviews	COPD	Community	Purposive	16 patients	Mean age 66.8	12M, 4F	Theory building (grounded theory)	To assess patients' concerns about accepting an offer of pulmonary rehabilitation
Hasson #58	2009	Canada	Interviews	COPD	Community	Care-givers screened against eligibility criteria. Those eligible who agreed to participate included.	9 care-givers	25-65	2M, 7F	Descriptive (content analysis)	To explore the experiences of palliative care that bereaved carers had while providing care to a dying loved one with COPD

Hasson #57	2008	UK	Interviews	COPD	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	13 patients	45-65	10M, 3F	Descriptive (content analysis)	To explore the potential for palliative care among people living with COPD
Hayle #59	2013	UK	Interviews	COPD	Specialist palliative care	Participants recruited against eligibility criteria. Those eligible who agreed to participate included.	8 patients	63-77	3M, 3F	Theory informed (phenomenological-hermeneutic approach)	To evaluate the experiences of patients with COPD who accessed palliative care
Heilem #61	2012	Norway	Interviews and focus groups	COPD	Pulmonary rehabilitation (outpatient)	Purposive	11 patients	53-68	3M, 8F	Theory informed (phenomenological approach)	To elucidate how patients with COPD who successfully maintain a long term exercise programme understand concordance with maintenance exercise and see potential solutions
Hogg, L. #62	2012	UK	Focus groups	COPD	Pulmonary rehabilitation (outpatient)	Purposive	16 patients	Patients divided into two groups. Group 1 = 71 (mean), Group 2 = 67 (mean)	9M, 7F	Theory building (grounded theory)	To understand the views and perceptions of patients with COPD regarding maintaining an active lifestyle following a course of pulmonary rehabilitation
Hopley #63	2009	New Zealand	Interviews	COPD	Community	Purposive	9 patients	50-80	Not stated	Descriptive (general inductive approach)	To understand the challenges people living with COPD in rural areas face in accessing specialist health care services
Hynes, G #65	2012	Ireland	Interviews	COPD	Community	Patients identified care-givers. All invited to participate. Owing to small numbers, further recruitment in patient support groups and advertisements in media.	11 care-givers	20-79	2M, 9F	Descriptive (thematic analysis)	To explore the experiences of informal caregivers providing care in the home to a family member with COPD
Jackson, #66	2012	Canada	Case study	COPD	Community	Convenience	4 patients	57-81	3F, 1M	Descriptive (thematic analysis)	To understand older patients with COPD experiences of their journeys through the health system
Jonsdottir #71	2007	Iceland	Serial interviews	COPD	Community	Convenience	7 patients	40-65	7F	Theory informed (interpretive phenomenology)	To explore the experience of women with advanced COPD of repeatedly relapsing to smoking
Kanervisto #72	2007	Finland	Interviews	COPD	Hospital	Participants selected by clinicians	5 patients, 4 spouses	Not stated	Patients = 3M, 2F. Spouses = 3F, 1M	Descriptive (deductive content analysis)	To describe the coping of the families of people with advanced COPD
Kaufman, #73	2014	USA	Focus groups	COPD	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	18 patients	49-75	12M, 6F	Descriptive (thematic analysis)	To describe the subjective sleep complaints of patients with COPD along with their attributions as to the cause of these symptoms and their treatment preferences for insomnia
Keating #74	2011	Australia	Interviews	COPD	Pulmonary rehabilitation (outpatient)	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	37 patients	53-86	18M, 19F	Descriptive (thematic analysis)	To understand what prevents people with COPD from attending and completing pulmonary rehabilitation
Kerr #75	2010	UK	Interviews	COPD	Pulmonary rehabilitation (outpatient)	All patients attending pulmonary rehabilitation invited to participate. Those who agreed to participate accepted on study.	9 patients	62-80	6M, 3F	Theory building (grounded theory)	To understand from an occupational perspective how patients live with COPD
Kvanvassnes #77	2013	Norway	Interviews	COPD	Acute hospital	Purposive	10 patients	45-85	5M, 5F	Descriptive (narrative analysis)	To explore patient perceptions of COPD exacerbation and experiences of their relations with health personnel during care and treatment
Lewis #79	2014	UK	Interviews	COPD	Pulmonary rehabilitation (community)	Convenience	25 patients	42-90	Not stated	Theory informed (interpretive phenomenological approach)	To explore the lived experience of COPD patients referred to pulmonary rehabilitation programmes prior to participation
Lewis #80	2010	UK	Focus group	COPD	Community	Purposive	6 patients	61-83	1M, 5F	Descriptive (thematic analysis)	To explore the attitudes of people with COPD to exercise and reasons for non-concordance with exercise maintenance post pulmonary rehabilitation
Lindgren #81	2014	Norway	Interviews	COPD	Community	Purposive	8 patients	60-74	3M, 5F	Theory informed (phenomenological-hermeneutic approach)	To illuminate patients' lived experiences of being diagnosed with COPD
Lindqvist #82	2013	Sweden	Serial interviews	COPD	Community	Purposive	21 spouses	53-84	21F	Theory informed (phenomenography)	To describe the conceptions of daily life in women living with a man suffering from COPD in different stages
Lindqvist #83	2010	Sweden	Serial interviews	COPD	Acute hospital	Open sampling initially then theoretical sampling in order to saturate emerging categories	23 patients	52-82	10M, 13F	Theory building (grounded theory)	To illuminate the main concern of patients with COPD and how they handle their everyday life
Lindqvist #159	2013	Sweden	Serial interviews	COPD	Community	Purposive	19 spouses	55-85	19M	Theory informed (phenomenography)	To describe the conceptions of daily life in men living with a woman suffering from COPD in different stages
Lomborg, K #86	2008	Denmark	Participant observation and interviews	COPD	Acute hospital	Patients screened against eligibility criteria and consecutively included. Further sampling selective and theoretical.	12 patients, 4 HCPs	Patients = >30. HCPs not stated	Not stated	Theory building (grounded theory)	To explore COPD patients' and nurses' expectations, goals and approaches to assisted personal body care.
Lundh, L. #87	2012	Sweden	Interviews	COPD	Community	Participants screened against eligibility criteria and recruited consecutively.	14 patients	47-83	7M, 7F	Theory building (grounded theory)	To investigate why some patients with COPD have difficulty quitting smoking and to develop a theoretical model that describes their perspectives on these difficulties.
Luz, E. L. #88	2013	Portugal	Interviews	COPD	Community	Convenience and theoretical sampling	22 patients	26-72	17M, 5F	Theory building (grounded theory)	To understand how people live with COPD
MacPherson, A. #89	2013	UK	Interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	10 patients	58-86	9M, 1F	Theory building (grounded theory)	To explore the views of people with severe COPD about advance care planning
Mahar, H. #90	2015	Denmark	Interviews	COPD	Community	Purposive	6 patients	67-83	3M, 3F	Descriptive (text condensation method)	To understand the experiences and preferences of COPD patients in relation to discharge from hospital with televised consultations
McMillan Boyles, C. #93	2011	Canada	Interviews	COPD	Community	Purposive	15 patients	>50	Not stated	Descriptive (narrative analysis)	To develop an understanding of the meaning of disability for individuals living with COPD
Meis, J #94	2014	Netherlands	Interviews and focus groups	COPD	Pulmonary rehabilitation (inpatient)	Patients screened against eligibility criteria. Those eligible who agreed to participate included. HCPs randomly invited to participate.	13 patients, 14 HCPs	Patients = 54-78. HCPs = 24-52	Patients = 8M, 5F. HCPs = 3M, 11F	Theory informed (descriptive phenomenological approach)	To assess COPD patients' experiences during an inpatient pulmonary rehabilitation program
Moore, #96	2012	UK	Interviews	COPD	Pulmonary rehabilitation (community)	Random sampling of three groups meeting different eligibility criteria. Patients recruited until data saturation had been achieved.	24 patients	47-84	14M, 10F	Descriptive (framework approach)	To assess the obstacles to participation in pulmonary rehabilitation among COPD patients in a community based pulmonary rehabilitation programme and associated general practices
Mousing #97	2012	Denmark	Interviews and focus groups	COPD	Community	Interviews: participants screened against eligibility criteria and then consecutively recruited until recruitment target met. Focus group: all participants attending patient education sessions invited to participate.	11 patients	51-75	3M, 8F	Descriptive (thematic analysis)	To explore how group patient education influences the self-care of patients with COPD
Nykvist #100	2014	Sweden	Interviews	COPD	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	6 patients	Not stated	6F	Descriptive (narrative analysis)	To describe how a group of smoking women with COPD experienced their everyday life and their relationship to smoking
Panos #107	2013	USA	Focus groups	COPD	Community	Participants were selected by systematic sampling against eligibility criteria and consecutively recruited until recruitment target met.	42 patients	48-88	42M	Descriptive (thematic analysis)	To determine the perceptions of veterans with COPD about their disease, its effects on their lives and their interactions with the Veterans' Healthcare Administration

Philio #108	2012	Australia	Interviews and focus groups	COPD	Acute hospital	Patients screened against eligibility criteria. Patients recruited consecutively until data saturation had been achieved. HCPs sampled purposively.	10 patients, 31 HCPs	Patients = 55-76. HCPs = 23-61	Patients = 6M, 4F. HCPs not stated	Descriptive (thematic analysis)	To explore the views of patients with COPD and HCPs focusing upon information needs and treatment preferences
Philip #109	2014	Australia	Interviews	COPD	Community	Care-givers identified by patient or physician. Those who agreed to participate included in study.	19 care-givers	28-83	3M, 10F	Descriptive (thematic analysis)	To understand the experiences and needs of family carers of people with severe COPD
Pinnock #110	2011	UK	Serial interviews and focus groups	COPD	Community	Purposive	21 patients, 13 care-givers, 18 HCPs	Patients = 50-83. Care-givers and HCPs not stated.	Patients = 14M, 7F. Care-givers and HCPs not stated.	Descriptive (thematic narrative analysis)	To understand the perspectives of patients with severe COPD as their illness progresses, and of their informal and professional carers
Reinke #112	2008	USA	Serial interviews	COPD or cancer	Community	HCPs: Drs screened against eligibility criteria, classified into specialty categories and then randomly selected. Nurses identified by patients or drs. Patients: identified by HCPs against eligibility criteria. Relatives: identified by patients.	55 patients, 56 HCPs, 36 relatives	Patients = 67.3 (mean), relatives = 60.3 (mean). HCPs = 47 (mean)	Patients = 22M, 33F. Relatives = 18M, 18F. HCPs = 22M, 34F	Theory building (grounded theory)	To examine participants' perspectives on the experiences of key transitions in the context of living with advanced COPD or cancer
Schroedl #117	2014	USA	Interviews	COPD	Acute hospital	Purposive	20 patients	52-83	9M, 11F	Descriptive (thematic analysis)	To understand the unmet health care needs among patients to help determine which aspects of palliative care are most beneficial.
Ssamrak #119	2012	UK	Interviews	COPD	Community	Patients screened against eligibility criteria. All eligible patient invited to participate.	16 patients	58-83	12M, 4F	Descriptive (content analysis and constant comparison)	To examine whether an admission to hospital for an exacerbation of COPD is an opportunity for advance care planning (ACP) and to understand, from a pt perspective, the optimum circumstance for ACP
Sheridan #121	2011	New Zealand	Interviews	COPD	Community	Pragmatic (8 patients initially interviewed, further participants from a certain ethnic group recruited in order to explore theme further)	29 patients	50-89	15M, 14F	Descriptive (thematic analysis)	To explore how patients with COPD experience helplessness
Shipman #122	2009	UK	Interviews	COPD	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included. 4 patients excluded post interview as did not meet eligibility criteria.	16 patients	54-86	9M, 7F	Descriptive (framework approach)	To explore factors that influence the use of general practice services by people with advanced COPD
Shum #123	2014	Canada	Interviews and focus groups	COPD	Community	Convenience	30 patients, 16 care-givers	Not stated	Not stated	Descriptive (thematic analysis)	To investigate how patients with COPD from new immigrant communities received and utilised information about their condition and its management
Simpson #125	2010	Canada	Interviews	COPD	Community	Purposive	14 care-givers	46-89	3M, 11F	Descriptive (interpretive description)	To understand the extent and nature of 'burden' experienced by informal care-givers in advanced COPD
Simson #156	2012	Canada	Serial dialogue	COPD	Community	Participants screened against eligibility criteria.	8 patients, 8 care-givers	Patients = 53-76. Care-givers not stated.	Patients = 4M, 4F. Care-givers = 3M, 5F	Descriptive (interpretive description)	To understand what is required for meaningful and effective advance care planning in the context of advanced COPD
Small #191	2012	UK	Interviews and focus groups	COPD	Community	Patients screened against eligibility criteria then randomly selected and invited to participate. Those eligible who agreed to participate included. Staff recruited from primary and secondary care with range of staff characteristically involved in COPD care (drs and nurses)	21 patients, 39 HCPs	Patients = 57-78. HCPs = 25-63	Split site study. Only one set of patients/HCPs reported on. Patients = 7M, 6F. HCPs = 6M = 6, F = 14	Descriptive (thematic analysis)	To report patients, family members and HCPs' experiences of COPD
Sorensen #128	2013	Denmark	Participant observation, interviews	COPD	Acute hospital	Participants screened against eligibility criteria. Those eligible who agreed to participate included. Recruitment continued until conceptual density achieved.	21 patients (obs) 11 patients (ints)	43-81	11M, 10 F	Theory building (grounded theory)	To present a theoretical account of the pattern of behaviour in patients with acute respiratory failure owing to COPD while undergoing non-invasive ventilation
Sossai #129	2011	Australia	Interviews	COPD	Community	Purposive	8 patients	50-85	5M, 3F	Descriptive (thematic analysis)	To explore the experience of living with COPD
Science #130	2008	UK	Interviews	COPD	Community	Purposive	7 care-givers	55-85	1M, 6F	Descriptive (content analysis similar to constant comparison)	To explore the specific care needs of informal care-givers of patients with advanced COPD
Strang #133	2013	Sweden	Interviews	COPD	Community	Purposive (maximum variation)	31 patients	48-85	15M, 16F	Descriptive (thematic content analysis)	To explore perceptions of anxiety and the alleviation strategies that are adopted by patients with COPD
Thorpe #137	2014	Australia	Interviews	COPD	Hospital	Purposive	28 patients	Mean age 71.86	22M, 6F	Descriptive (content analysis)	To explore the barriers to and enablers of participation in physical activity following hospitalisation for COPD
Torheim #138	2010	Norway	Interviews and focus groups	COPD	Acute hospital	Purposive	5 patients, 8 nurses	Patients = 45-78. Nurses not stated.	Patients = 2M, 3F. Nurses not stated.	Theory informed (phenomenological approach)	To explore the experiences of mask treatment in patients with acute exacerbations of COPD
Torheim #139	2014	Norway	Interviews	COPD	Acute hospital	Strategic (recruited to meet eligibility criteria)	10 patients	45-85	5M, 5F	Theory informed (phenomenological approach: meaning condensation)	To gain insight how patients with advanced COPD experience care in the acute phase (specifically in the intensive care unit)
Willcocks #145	2012	UK	Interviews	COPD	Community	Purposive (nonprobabilistic)	14 patients	Mean age 62.3	5M, 9F	Descriptive (thematic network analysis)	To elicit and describe the first-hand experiences of anxiety in community patients with stable COPD
Williams #147	2010	UK	Interviews	COPD	Pulmonary rehabilitation (outpatient)	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	9 patients	54-84	6M, 3F	Theory building (grounded theory)	To explore how pulmonary rehabilitation affects the experience of activity and breathlessness of people with COPD
Williams #146	2007	UK	Interviews	COPD	Community	Purposive	6 patients	64-83	4M, 2F	Descriptive (thematic analysis)	To investigate what is most important to people living with COPD
Williams #148	2011	UK	Interviews	COPD	Community	Purposive and theoretical sampling	18 patients	54-84	12M, 6F	Theory building (grounded theory)	To understand how people with COPD experience activity
Wilson #150	2008	Canada	Serial interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	12 patients	Not stated	Not stated	Descriptive (constant comparison approach)	To determine the care needs of seniors living at home with advanced COPD
Wilson #152	2007	UK	Focus groups	COPD	Community	Purposive	32 patients, 8 HCPs	Patients = 56-82. HCPs not stated.	Patients = 25M, 7F. HCPs not stated.	Theory building (grounded theory)	To ascertain what should be included in the educational component of pulmonary rehabilitation
Wodaku #153	2014	Denmark	Interviews and focus groups	COPD	Community	Purposive	34 patients, 8 relatives	Patients = 48-87; Relatives = not stated	Patients = 15M, 9F. Relatives = 3M, 5F	Descriptive (content analysis)	To examine the experiences of COPD patients and their relatives of integrated care

Author	Year	Country	Qual method	Index condition	Setting	How sampled?	Sample	Age of sample	Gender of sample	How data analysed?	Study details
Amichai #3	2012	Canada	Interviews	Lung cancer	Acute hospital	Purposive	12 patients	40-70	6M, 6F	Descriptive (interpretative)	To understand lung cancer patients' beliefs about complementary and alternative medicine use in promoting their own wellness
Arber #226	2013	UK	Interviews	Lung cancer	Acute hospitals	Theoretical sampling until data saturation achieved	10 patients	56-82	8M, 2F	Theory building (grounded theory)	To explore patients' experience during the first 3 months following a diagnosis of malignant pleural mesothelioma
Baker #8	2012	UK	Interviews	Breast, lung or prostate cancer	Acute hospitals	Purposive. Recruitment continued until theoretical saturation reached.	42 patients	36-86	23M, 19F	Descriptive (constant comparison technique)	To investigate the readiness of patients to address emotional needs up to 18 months following a diagnosis of cancer
Bertero #11	2008	Sweden	Interviews	Lung cancer	Acute hospitals	Purposive	23 patients	36-86	12M, 11F	Theory informed (phenomenological-hermeneutic approach)	To describe how having inoperable lung cancer affects the patients' life situation and quality of life
Brown #300	2015	Australia	Interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	10 patients	50-89	8M, 2F	Theory building (grounded theory)	To explore the supportive care needs and preferences of lung cancer patients
Carrion #16	2013	USA	Interviews	Lung, brain, colorectal, prostate cancer	Community	Purposive	15 patients (2 living with lung, 2 brain, 2 colorectal, 9 prostate)	31-71	15M	Descriptive (thematic analysis)	To explore beliefs and treatment decisions of Latino men with cancer
Caughlin #160	2011	USA	Interviews	Lung cancer	Community	Participants recruited by advertisement and screened against eligibility criteria. Those who agreed to participate, included.	35 family members	36-72	6M, 29F	Theory building (grounded theory)	To examine families' communication and coping in response to a parent's lung cancer
Dale #161	2011	UK	Interviews	Lung cancer	Palliative care	Purposive	6 patients	67-81	2M, 4F	Descriptive (thematic analysis)	To explore the concerns of patients with inoperable lung cancer
Dorman #112	2009	UK	Interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included. Recruitment continued until no new themes emerged.	9 patients	Not stated	5M, 4F	Theory informed (Interpretative Phenomenological Analysis)	To study what patients with recently diagnosed brain metastases from NSCLC want from their treatment
Epiphaniou #270	2014	UK	Serial interviews	Lung cancer and COPD	Acute hospital	Purposive	18 patients (11 living with lung cancer, 7 COPD)	52-90	12M, 6F	Descriptive (thematic analysis)	To explore patients' experience of care coordination in COPD and lung cancer
Eustache #271	2014	Canada	Interviews	Lung cancer	Cancer centre	Purposive (maximum variation)	12 patients	36-78	6M, 6F	Descriptive (interpretative)	To explore the experience and meaning of hope in relation to the healing process of patients living with lung cancer
Farley #349	2015	UK	Interviews	Lung cancer	Acute hospital	Purposive	22 patients	39-82	12M, 10F	Descriptive (framework approach)	To explore lung cancer patients' views about smoking and about their preferences for support to help them quit
Gerber #195	2012	USA	Focus groups	Lung cancer	Cancer centre/acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	13 patients	39-69	7M, 6F	Descriptive (thematic content analysis)	To gain insight into patients' perceptions of maintenance chemotherapy
Hamilton #135	2010	USA	Focus groups	Lung, colon, breast, other cancer	Outpatient oncology clinics	Purposive. Recruitment continued until theoretical saturation reached.	22 patients (4 living with lung, 9 breast, 2 colon, 7 other)	50-80	7M, 15F	Theory building (grounded theory)	To explore the perceived social support needs among older African American cancer survivors
Hendriksen #312	2015	USA	Interviews	Lung cancer	Cancer centres	Patients screened against eligibility criteria. Care-givers nominated by patient and screened against eligibility criteria.	11 patients, 10 care-givers	Patients = 36-78. Care-givers = 34-74	Patients = 8F, 3M. Care-givers = 5F, 5M	Theory building (grounded theory)	To explore the nature of shared anxiety and its impact on patient-caregiver dyads
Hoff #64	2014	Sweden	Serial interviews	Malign haematological disease or lung cancer	Acute hospitals	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	12 patients (5 living with lung, 7 haematological)	37-80	5M, 7F	Descriptive (content analysis)	To identify challenges in communicating with patients with lung cancer about their imminent death
Hoffman #276	2014	USA	Focus groups	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	6 patients	53-73	2M, 4F	Descriptive (directed content analysis)	To identify the postsurgical NSCLC patients' unmet supportive care needs during transition from hospital to home
Horne #50	2006	UK	Interviews	Lung cancer	Community	Purposive	9 patients	52-87	3M, 6F	Theory building (grounded theory)	To develop and pilot an advance care planning intervention for lung cancer nurses
Horne #200	2012	UK	Interviews	Lung cancer	Cancer centres	Purposive	25 patients, 19 family members	47-85 (patients). Family members not stated	18M, 7F. Family members not stated.	Theory building (grounded theory)	To explore the views and experiences of people affected by lung cancer about discussing preferences and wishes for end of life care and treatment
John #141	2010	USA	Interviews	Lung cancer	Cancer centres	Purposive	10 patients	48-87	6M, 4F	Descriptive (content analysis)	To describe self care strategies used by patients with lung cancer to promote quality of life
Krishnasamy #68	2007	UK	Serial interviews	Lung cancer	Cancer centres	Participants screened against eligibility criteria. Those eligible, who wished to participate, included. Recruitment continued until data saturation achieved.	60 patients, 31 family members	Patients = 38-82. Family members not stated.	Patients = 32M, 28F. Family members = 4M, 27F	Theory building (grounded theory)	To explore the experiences of care provision of patients with lung cancer and their carers

Lee #120	2009	Australia	Case study report	Lung cancer	Community	Convenience	2 patients, 6 care-givers, 5 HCPs	Not stated	Not stated	Descriptive (constant comparison technique)	To identify common issues and to explore the needs and experiences of people with lung cancer, their carers and service providers
Lehto #283	2014	USA	Focus groups	Lung cancer	Community hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	11 patients	51-79	5M, 6F	Descriptive (thematic analysis)	To describe the lung cancer experience in relation to perceived stigmatization, smoking behaviours and illness causes
Lowe #570	2011	UK	Serial interviews	Lung cancer	Cancer centre	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	17 patients, 15 care-givers	Patients = 48-93. Care-givers = 40-81	Patients = 12M, 5F. Care-givers = 5M, 10F	Theory informed (Interpretative Phenomenological Analysis)	To explore factors that influence patient distress within the lung cancer population
Lowson #571	2013	UK	Interviews	Heart failure, lung cancer	Acute hospital and community	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	27 patients (14 living with lung, 13 heart failure)	69-89	13M, 14F	Descriptive (framework approach, thematic analysis)	To explore the meanings of family caring for care recipients
Maguire #576	2014	UK	Interviews	Lung cancer	Acute hospital	Purposive	10 patients	47-80	4M, 6F	Theory informed (Interpretative Phenomenological Analysis)	To explore the lived experience of multiple concurrent symptoms in people with lung cancer
McCarthy #587	2009	Ireland	Interviews	Lung cancer	Acute hospital	Purposive	6 patients	53-74	2M, 4W	Theory informed (Interpretative Phenomenological Analysis)	To explore patients' experiences of living with NSCLC
Missel #597	2015	Denmark	Interviews	Lung cancer	Acute hospital	Criteria sampling approach (to select cases of predetermined criteria of importance)	19 patients	42-79	7M, 12F	Theory informed (Ricoeur's theory of interpretation)	To investigate how the diagnosis affects the daily lives of patients with operable lung cancer
Molassiotis #598	2011	UK	Serial interviews	Lung cancer	Cancer centre	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	17 patients, 15 care-givers	Patients = 48-93. Care-givers = 40-81	Patients = 12M, 5F. Care-givers = 5M, 10F	Theory informed (Interpretative Phenomenological Analysis)	To explore lung cancer patients experiences of symptom clusters
Mosher #604	2015	USA	Interviews	Lung cancer	Cancer centre	Purposive	21 patients, 21 care-givers	Patients = 39-80. Care-givers = 38-78	Patients = 10M, 11F. Care-givers = 6M, 15F	Descriptive (thematic analysis)	To identify strategies for coping with various physical and psychological symptoms among advanced symptomatic lung cancer patients and their primary family care-givers
Petri #758	2015	Denmark	Interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	3 patients	65-72	2M, 1F	Theory informed (descriptive phenomenology)	To explore and describe the essential meaning of lived experiences of everyday life during curative radiotherapy in patients with NSCLC
Pollock #760	2008	UK	Serial interviews	Lung cancer and head & neck	Acute hospital	Patients screened against eligibility criteria. Those eligible, who wished to participate, included. Family members nominated by patients.	27 patients (15 living with lung, 12 H&N), 20 family members	Patients = 41 - 85. Family members not stated	Patients = 23M, 8F	Descriptive (thematic analysis)	To investigate service users' experiences of information delivery after a diagnosis of cancer
Powell #763	2015	UK	Interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	15 patients	58-87	5F, 10M	Descriptive (framework approach)	To explore patients' attitudes to the risks associated with lung cancer surgery
Robinson #777	2011	Canada	Interviews	Lung cancer	Community	Participants screened against eligibility criteria. Family members nominated by patients.	9 patients, 9 family members	Not stated	Not stated	Descriptive (constant comparison technique)	To explore the applicability and usefulness of an advanced care planning (ACP) intervention and examine the ACP process
Salander #786	2014	Sweden	Serial interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria and consecutively included.	15 patients	56-85	4M, 11F	Descriptive (constant comparison technique)	To understand how patients with lung cancer reflect upon their life situation after diagnosis and treatment
Sandeman #789	2011	UK	Interviews	Lung cancer	Acute hospital	Purposive	10 patients	46-82	4M, 6W	Descriptive (framework approach)	To explore the experiences of lung cancer patients attending routine follow up
Sjolander #931	2008	Sweden	Interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	10 patients	47-88	8M, 2F	Descriptive (constant comparison technique)	To identify and describe the impact that social support and a social network has for patients with lung cancer
Steinval #938	2011	Sweden	Interviews	Lung cancer	Acute hospital	Purposive	11 family members	56-73	7M, 4F	Theory informed (phenomenological-hermeneutic approach)	To identify and describe the experiences of quality of life/life situation among those who were next of kin to persons with inoperable lung cancer
Stone #941	2012	USA	Interviews	Lung cancer	Community	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	35 family members	36-72	6M, 29F	Descriptive (constant comparison technique)	To investigate communication and care in the context of lung cancer
Thornton #948	2011	UK	Interviews	Lung cancer	Cancer centre	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	5 patients	39-67	4M, 1F	Descriptive (thematic content analysis)	To explore the factors that influence patients' choice of treatment during the oncologist-patient consultation
Treloar #957	2009	Australia	Focus groups	Lung cancer	Acute hospitals	Participants screened against eligibility criteria. Recruitment continued until no new themes emerged.	22 patients, 13 care-givers	Patients = 37-83. Care-givers = 39-75	Patients 17M, 5 F. Care-givers = 1M, 12F	Descriptive (thematic analysis)	To identify the needs of people with NSCLC and their carers in relation to quality of life issues
Wickersham #975	2014	USA	Interviews	Lung cancer	Cancer centre	Purposive	13 patients	52-83	5M, 8F	Theory building (grounded theory)	To explore the process of medication-taking for NSCLC patients receiving oral epidermal growth factor receptor inhibitors

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Patients and informal caregivers' experiences of burden of treatment in lung cancer and chronic obstructive pulmonary disease (COPD): a systematic review and synthesis of qualitative research

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ABSTRACT.

Objective:

To identify, characterise and explain common and specific features of the experience of treatment burden in relation to patients living with lung cancer or chronic obstructive pulmonary disease (COPD) and their informal caregivers.

Design:

Systematic review and interpretative synthesis of primary qualitative studies. Papers were analysed using constant comparison and directed qualitative content analysis.

Data sources:

CINAHL, EMBASE, MEDLINE, PsychINFO, Scopus and Web of Science searched from January 2006 to December 2015.

Eligibility criteria for selecting studies:

Primary qualitative studies in English where participants were patients with lung cancer or COPD and/or their informal caregivers, aged >18 that contain descriptions of experiences of interacting with health or social care in Europe, North America and Australia.

Results:

We identified 127 articles with 1,769 patients and 491 informal caregivers. Patients, informal caregivers and healthcare professionals (HCPs) acknowledged lung cancer's existential threat. Managing treatment workload was a priority in this condition, characterised by a short illness trajectory. Treatment workload was generally well supported by an immediacy of access to healthcare systems and a clear treatment pathway. Conversely, patients, informal caregivers and HCPs typically did not recognise or understand COPD. Treatment workload was balanced with the demands of everyday life throughout a characteristically long illness trajectory. Consequently, treatment workload was complicated by difficulties of access to, and navigation of, healthcare systems, and a fragmented treatment pathway. In both conditions, patients' capacity to manage workload was enhanced by the support of family and friends, peers and HCPs and diminished by illness/smoking related stigma and social isolation.

Conclusion:

This interpretative synthesis has affirmed significant differences in treatment workload between lung cancer and COPD. It has demonstrated the importance of the capacity patients have to manage their workload in both conditions. This suggests a workload which exceeds capacity may be a primary driver of treatment burden.

Systematic review registration number:

PROSPERO CRD42016048191

Strengths and limitations of this study:

- To the best of our knowledge, this is the first systematic review and synthesis that compares treatment burden in malignant and non-malignant disease
- The review synthesises patient and informal caregiver experience of treatment burden across a wide range of healthcare settings and systems
- The heterogeneity of studies included means uniformities highlighted should facilitate the development of an explanatory model of burden of treatment
- The data analysed, whilst ostensibly from primary sources, are seen through the multiplicity of theoretical lenses chosen by the studies' authors and their varying epistemological and ontological stances and, indeed, the authors' own which may be a limitation of the study

Introduction:

Burden of treatment (BoT) is not simply the unavoidable workload that illness inevitably confers on patients and their informal caregivers but is a potentially *modifiable* workload which treatment for the illness may create (1). This workload consists of affective, cognitive, informational, material, physical and relational tasks delegated to patients and/or their informal caregivers by HCPs (1, 2). The literature on BoT discusses the concept of “capacity” and defines this as the resources (which may be affective, cognitive, informational, material, physical and relational) and limitations that affect patients’ capability to carry out the work of chronic illness (1, 3, 4). Capacity may be viewed at an individual (i.e. the patient) or collective level (i.e. the patients’ social network) (5). Capacity may be affected by a range of variables, from socio-economic factors such as ethnicity and poverty, to the social skill necessary to engage and mobilize stakeholders (1-4, 6-12). A workload that exceeds capacity might, in some cases, be a primary driver of BoT for patients (1, 4). Neither workload nor capacity are static. They may fluctuate over time as illness progresses, functional capacity declines and patients’ social networks change (1, 3, 4) or, indeed, as the patient is able to accept, adapt and normalise their condition into their daily life (2, 9, 12, 13).

The literature (1, 7, 11, 14, 15) emphasises the importance of adequately equipping clinicians with tools to detect BoT and training in interventions that might ameliorate burden in order to provide “minimally disruptive medicine” (15). This is an approach to healthcare that takes into account patient priorities, multi-morbidity and seeks to reduce the BoT on the patient and informal caregiver (15).

COPD and lung cancer are the most common causes of respiratory-related mortality in the United Kingdom (UK), excluding pneumonia (16). Tobacco smoking is the main risk factor for both diseases, linked to an estimated 86% of lung cancer and 90% of COPD cases in the UK (17, 18). Thus, both may carry the stigma of a ‘self-inflicted’ disease (19, 20).

Tobacco is a legal drug, used commonly, and has been previously socially acceptable. More recently, recognition of the significant risks of tobacco smoking and public health strategies to ‘de-normalise’ tobacco have contributed to a social transformation that actively stigmatizes smokers (21).

COPD generally has a protracted trajectory of increasing respiratory limitation, punctuated by recurrent episodes of worsening termed “exacerbations”. Globally, COPD is a major cause of chronic morbidity and mortality; prognosis is uncertain but many people die prematurely because of the disease or its complications (such as pneumonia) (22). Conversely, lung cancer typically has a rapid trajectory involving steady progression with a clear terminal phase (23). The prognosis for lung cancer is poor; only 1 in 10 patients in the UK live for more than 5 years after diagnosis. Lung cancer treatments in England are predominantly hospital-based: outpatient chemotherapy or systemic anti-cancer treatment or inpatient surgical treatment (24). In contrast, treatment for COPD generally involves self-management (management of treatment regimens by patients and informal caregivers in the home) (25). BoT may, therefore, be experienced very differently by patients living with these two common respiratory conditions.

Aim of the review:

We aimed to undertake a comprehensive search of the literature to identify, characterise and explain common and specific features in the experiences of treatment burden in relation to patients living with either lung cancer or COPD.

Research question:

What is burden of treatment in lung cancer and COPD and how is it experienced by patients and their informal caregivers?

Methods:

Identifying relevant studies:

This review forms part of a larger body of work which we are undertaking in order to identify, characterise and explain the intricate interpersonal and institutional processes that mediate patient and informal caregiver experiences of their interactions with healthcare. Thus, for this study we replicated and extended a previously developed search strategy which was built around three search concepts (26):

- (i) index conditions (heart failure, chronic kidney disease and COPD)
- (ii) qualitative research methodology terms
- (iii) patient/informal caregiver experience.

The full search strategy as performed in MEDLINE is available in Appendix 1. The search was piloted in MEDLINE and then adapted for other electronic databases used (CINAHL, Embase, Scopus, Web of Science, PsycInfo). We looked at primary qualitative studies examining patients with COPD and lung cancer and their informal

caregivers' interactions with health and social care, rather than studies which explicitly examine treatment burden in COPD or lung cancer as there are so few. Searches were limited to countries with advanced healthcare systems comparable to the UK as the synthesis is intended to inform a future research project that will take place in the National Health Service (NHS) in England. We limited our search to publications from the year 2006 onwards. This is because, like Gallacher et al (7), we wanted to locate patient/informal caregiver experiences of BoT in current rather than historical health and social care practices. After retrieving and screening full text articles, we excluded mixed methods studies as the majority of these studies screened suggested the qualitative components of the studies addressed a very specific research question, meaning that there was little data relevant to our research question. This is a potential limitation of the systematic review as there is a possibility that we have missed some pertinent studies. Table 1 details inclusion/exclusion criteria.

Study selection:

KAL, MM, AC and CRM individually screened batches of citations and abstracts to assess eligibility against the inclusion/exclusion criteria. A third reviewer (JH, see acknowledgements) resolved eligibility disagreements at this stage. We obtained studies in full text where it was not immediately possible to determine eligibility against inclusion/exclusion criteria. KAL, MM AND JH independently double screened all full-text COPD articles for eligibility; KAL screened all full-text lung cancer articles for eligibility with 10% of the full text papers screened by CRM. A third reviewer (KH, see acknowledgements) resolved eligibility disputes at this stage.

Quality assessment:

MM, AC, JH and KAL undertook quality assessment of included papers using a modified version of the qualitative appraisal tool: RATS (relevance, appropriateness, transparency, soundness) (27)(see Appendix 2) guidelines. We took a conservative approach to assessment, primarily undertaking it to ensure transparency of study design, aims and the sampled population. Thus, we excluded only five of the lung cancer studies that had not appeared to seek ethical permissions.

Data extraction and analysis:

We extracted data from the findings/results, discussion and conclusion sections of each paper. Extracted data included verbatim quotes from patients and caregivers and authors' interpretations (2). As the aim of the review was to identify and characterise patient and informal caregiver experience, we omitted results relating to HCPs in the analysis (n=12 of studies included HCPs). CRM, AR, KAL, MM, AC and JH developed a coding framework, underpinned by robust, empirically derived, middle-range theories: BoT theory (described above) (1) and status passage theory (28). Middle range theories are applicable to discrete conceptual ranges, sitting between frequently generated minor working hypotheses and all-encompassing efforts to explain systematically the observed uniformities of society. They may be particularly helpful, therefore, in generalising learning in health services improvement so that interventions can be replicated in different contexts (29). Status passage theory describes people as constantly in passage between temporally limited and societally ascribed statuses (for example, from being unmarried to married). Status

passages may (or may not) be desirable, inevitable, reversible, repeatable or voluntarily undertaken. They may vary in their importance to the person undergoing the passage. Passages may have to be legitimized by authorized agents. Status passage theory is a particularly useful tool when considering illness, which is an undesirable, involuntary and often irreversible passage, legitimized by HCPs as authorized agents (28).

In keeping with the principles of directed qualitative content analysis which seeks to extend conceptually an existing theory, we identified key concepts of BoT and status passage theories as coding categories and determined operational definitions for these creating a coding framework (30). KAL, MM, AC and JH then independently used the coding framework to code a selected group of data and compared results. Once inter-coder reliability had been established, KAL downloaded full-text articles into the qualitative data analysis software Nvivo 11, used to organise and manage data. KAL read the full text versions of identified papers to enable immersion in the data to understand their scope and context (31). and coded data using the coding framework described above. KAL, supported by CRM and AR analysed data using directed qualitative content analysis (30) and constant comparison (32). We grouped related codes into sets for each condition and compared sets within and between conditions. We used Shippee et al's (4) proposition that a workload that exceeds capacity might be the primary driver of BoT.and thus grouped coded data into sets of **workload** (the affective, cognitive, informational, material and relational tasks delegated to patients/caregivers) and **capacity** (the affective, cognitive, informational, material and relational resources available to be mobilized by patients/caregivers). We then formulated simple explanatory propositions with which

to characterise differences and similarities in treatment burden between conditions. These propositions, with coded data as supporting evidence, were used to develop a taxonomy which identifies and characterises primary and secondary constructs of BoT in lung cancer and COPD (Table 2).

Patient and public involvement:

Our wider National Institute for Health Research (NIHR) funded programme of research on complexity, patient experience and organisational behaviour has been developed in engagement with three groups in which more than 40 patients and caregivers have played a substantial role. In this particular study we worked closely with the late Mark Stafford-Watson (see acknowledgements). He played a valuable role in the development of the research question. Emerging results from this systematic review have been discussed with members of a local Breathe Easy (British Lung Foundation patient support group), and these discussions have informed the development of empirical research following the review

Results:

Characteristics of studies:

Figures 1 and 2 show each stage of the review process. We identified 127 articles: 85 COPD and 42 lung cancer. The papers included 1,233 COPD patients, 251 informal caregivers of COPD patients; 536 lung cancer patients and 240 informal caregivers of lung cancer patients. The majority of the papers were set in the UK, USA, Canada and Sweden. Ninety nine papers used qualitative interviews, 14 used interviews alongside either participant observation or focus groups. Eleven studies employed focus groups, two studies used case study and one study used serial dialogue. Further characteristics of studies are available in Appendix 3.

Workload (primary construct):

Diagnosis (secondary construct):

For the majority of patients with COPD, the experience of receiving a diagnosis of COPD was not a memorable event (33-46) ; “a story without a beginning” (43). Often, patients had never received a formal diagnosis or were not informed of their diagnosis for many years. One study described how its participants questioned why they were recruited, unaware that they had been diagnosed with COPD (42). Even when given a diagnosis, many patients often did not understand the term ‘COPD’: “...as I say, I wasn’t even sure, it had never been put to me, formally put to me that I’d got this obstructive pulmonary or whatever they call it” (35) (p.706).

In contrast, patients with lung cancer almost universally described the moment of diagnosis as a “shock” (47-53), an unexpected and undesirable “crisis” which “flooded” patients’ lives (28). Patients felt overwhelmed by the existential threat of cancer that took away their ability to plan for or even imagine a future (48, 54, 55).

Illness identity (secondary construct):

Several studies demonstrated a lack of public understanding of COPD (33-35, 37, 39, 42, 43, 45, 56-59). Thus, patients and their informal caregivers often had not heard of COPD prior to diagnosis and therefore had no expectations of the disease and its likely trajectory: “When cancer was excluded all worries about the future or fear of death fell away” (34) (p.558). Conversely, cancer has a recognisable public narrative, replacing tuberculosis as the disease the public most fears (60-63). In several of the studies, the patient’s experience reflected this narrative shift (50, 53, 64): “Patients acknowledged despair.and.hoped for an alternative diagnosis: “It doesn’t have to be lung cancer... it doesn’t have to be the worst”” (64) (p.1207).

Attitude towards treatment (secondary construct):

Consequently, treatment for the illness – often became the overriding priority in life for patients with lung cancer (64-67), suspending the demands of everyday life: “Life is immediately put on hold...so a normal everyday life didn’t concern me because everything revolved around treatment and only completion of the treatment was important so everything else didn’t matter” (66) (p.5). Conversely, patients often saw COPD as a “way of life” (43) not an illness. The management and treatment of ‘stable’ COPD symptoms was seen as something that had to be integrated into everyday life rather than being a priority (35, 43, 57, 59, 68-73). Many patients with COPD, even with advanced illness, did not regard themselves as unwell (43, 59, 70, 71, 73). Patients reported exacerbations of COPD as ‘proper’ illnesses but saw the often debilitating symptoms of ‘stable’ COPD as a normal part of life, something to be accepted and coped with (70).

In the papers included, patients often described COPD as a “planning” disease, balancing the work of everyday life with the material demands of managing their treatment workload (42, 72, 74-79). This was complicated by the uncertainty of the illness trajectory making disease fluctuations difficult to anticipate and, consequently, to manage (33, 37, 39, 70, 80-84). Less commonly, patients with lung cancer also described the importance of planning and managing their own treatment workload (47, 66, 67, 85-87). More commonly, patients with lung cancer were overwhelmed by the debilitating pathophysiological side effects of their treatment such as breathlessness, fatigue, nausea and vomiting and were unable to focus on anything apart from treatment completion (48, 55, 65-67, 86, 88-92). Nonetheless, patients with lung cancer often experienced the practical demands of treatment – the treatment workload – as a relief, despite these potentially incapacitating

1
2
3 pathophysiological side effects (51, 53, 86, 93). Patients repeatedly used the
4 metaphor of treatment as “hope”, a lifebelt in the existential flood caused by the
5 diagnosis of lung cancer (49, 51, 64, 86, 87, 91, 94, 95). Indeed, some patients
6 reported a sense of “limbo” once the practical workload of treatment had finished
7 (48, 66, 96-98). This “limbo” was both existential (66, 98): “Now I have lived for
8 something, to complete and survive the treatment and suddenly the priority of life is
9 gone” (66) (p.5) or structural, where patients felt in transition between healthcare
10 institutions (48, 96, 97). Thus, paradoxically, patients with lung cancer could report a
11 reluctance to stop treatment, despite its unpleasant pathophysiological side effects :
12 “I’ll keep taking chemo as long as you’ll give it to me” (86) (p.105). Some patients
13 with lung cancer also described continuing with treatment because they believed it
14 was what their family wanted, rather than consulting their own preferences (67, 87,
15 99).

16
17 Patients with COPD reported how elements of treatment that supported self-
18 management (for example, educational sessions at pulmonary rehabilitation (PR))
19 provided a much needed sense of control over their condition (35, 72, 78, 100-107).
20 Yet, it was evident how fragile this sense of control might be, easily undermined by
21 structural disadvantages such as transitions between healthcare institutions and lack
22 of communication from and between HCPs (33, 37, 41, 58, 73, 108, 109):

23
24 “I said, put them bloody tablets back [after one of usual medications stopped
25 in hospital, followed by him feeling unwell]. Don’t take stuff off me without
26 telling me. And I swore at him, [hospital doctor] I did, I was blazing. For giving
27 me a dodgy thing again. But that’s what you’ve got to put up with you see.”
28 (41) (p.269)

This suggests unsupported and undermined self-management may be an exhausting and frightening, rather than empowering experience for the patient and their informal caregiver. Indeed, in the studies included, patients with COPD repeatedly describe the relief of respite from the demands of self-management that institutionally provided treatment (specifically hospitalization, PR, day hospice and specialist outpatient care) brings (57, 58, 84, 104, 109-119):

“Sometimes you can think, when you’re too sick, that they [medical staff] can tell me what to do, so I don’t have to make all the decisions. I trust myself, but it would be nice if someone just took care of me like that.” (111) (p.1485)

However, particularly in the case of hospitalization, institutionally provided treatment might also significantly add to the workload of patients with COPD. Patients reported a hospital stay as a chaotic, confusing and disruptive experience. They felt they were seen as “low priority” by the healthcare provider and frequently moved from ward to ward (41, 79, 116, 120). Thus, some patients might try to avoid hospitalization (37, 41, 120).

Identifying and accessing treatment options (secondary construct):

In the papers included, patients with lung cancer reported frequently having to make decisions about whether or not to have treatment, which they repeatedly phrased as a lack of choice: a choice between death or treatment (67, 91, 93, 97, 121). Whilst ostensibly involved in the treatment decision-making process, some patients described having little real control over treatment options, believing they lacked the cognitive ability and specialist knowledge required to make informed treatment decisions (93, 97, 99). Indeed, frequently patients reported choosing to cede the cognitive burden of decision-making over treatment options to a trusted HCP (86, 93, 97, 99, 121, 122).

For patients with COPD, identification of treatment options could, itself, be problematic (35, 57, 70, 113, 123). Patients described being repeatedly told that “nothing could be done for them” by HCPs in both primary and secondary care (35, 57, 70, 113, 123). Thus, papers reported patients identifying treatment options from other sources of information such as the experience of peers or through their own research (56, 57, 68, 108, 113). Once treatment options were identified, patients could experience difficulty in accessing them (34, 35, 39, 40, 42, 44-46, 58, 70, 73, 74, 76, 103, 108, 109, 116, 120, 124-130).

Access to and navigation of healthcare institutions/systems (secondary construct):

After diagnosis, patients with lung cancer frequently reported rapid access to healthcare institutions and specialist HCPs who recognised and understood lung cancer and were able to co-ordinate its treatment workload (49, 67, 85, 121, 131, 132). Furthermore, patients with lung cancer appeared to follow a relatively structured treatment pathway (49, 53, 66, 67, 85, 121, 131, 132). In contrast, patients with COPD described encounters with gatekeeping generalist HCPs who did not recognise or understand their disease (44, 45, 58, 78, 109, 112, 113, 116, 124, 126, 129) and, consequently, significant delays in accessing specialist care. Patients with COPD reported the hard work of accessing healthcare, having to navigate between primary and secondary care, in a fragmented system, lacking a clear COPD treatment pathway (34, 37, 42, 44, 45, 58, 73, 74, 76, 103, 108, 109, 116, 120, 126, 127, 129). Furthermore, patients described being expected to act as custodians of their own medical history, having to update HCPs with changes to their treatment (109, 133).

Practical workload of treatment (secondary construct):

Once treatment options were identified and accessed, patients with both conditions reported experiencing a significant practical workload, with multiple appointments for treatment, most commonly in hospitals for cancer (52, 91, 134) and occurring in a variety of settings for COPD (73, 101, 108, 120, 123, 125, 133, 135). Patients with both conditions described structural disadvantages such as the availability and cost of transportation and parking, physical restrictions in accessing healthcare (such as stairs), waiting for appointments and restricted time for appointments with HCPs that make their workload more onerous (34, 39, 42, 52, 58, 73, 91, 101, 108, 109, 120, 123, 125, 126, 129, 134, 135).

Patients with COPD and their informal caregivers reported being delegated a wide range of material treatment tasks by HCPs to self-manage at home. These included the management of complex medication regimens (33, 35, 42, 72, 74-76, 80, 109, 129, 130, 136), the operation of technologies such as oxygen (42, 45, 58, 59, 73, 79, 83, 106, 108, 109, 126, 127, 136-143), nebulisers (33, 68, 80, 126, 127, 140) and non-invasive ventilation (69, 144). These also included self-management of the illness itself: avoiding exacerbation triggers, monitoring physical symptoms and help-seeking when appropriate (35, 37, 68, 72-74, 76, 80, 103, 114, 130, 133, 145). In contrast, patients with lung cancer described receiving highly specialised, predominantly hospital-based therapies with little delegation of material treatment tasks (48, 50, 52, 53, 65-67, 86, 89, 91, 93, 97-99, 121, 131, 146). The exception was a study interviewing patients receiving oral targeted therapies who described the rigorous process they underwent when securing and taking medication (87). This paper highlighted the priority patients with lung cancer gave to their treatment

because of the recognition of lung cancer’s immediate threat to life as they rigidly adhered to their delegated task (87).

Informational workload of treatment (secondary construct):

Patients with both conditions described being required to comprehend a large amount of information about their treatment (35, 37, 51, 56, 64, 66-68, 73, 83, 85, 88, 89, 94, 96, 97, 99, 103, 108, 121, 130, 132, 133, 136, 141, 147-150). Commonly, patients with lung cancer felt that high quality information about their treatment was available to them when they required it (64, 67, 85, 93, 97-99, 121, 132, 147, 148, 151). Nonetheless, the “shock” of diagnosis meant some patients struggled to retain or process information about treatment and therefore felt that further information was required once they began to assimilate their diagnosis (53).

Some patients with lung cancer wanted to be fully informed about their condition and treatment by their HCP, including prognosis, however bleak this was (67, 85, 98, 121, 132, 147, 148). In contrast, other patients found being fully informed overwhelming and frightening, particularly when given comprehensive written materials (53, 97, 147). They wanted limited information from HCPs, appearing to use this as a coping strategy to maintain hope for as long as possible, (48, 51, 64, 66, 97, 99, 121, 122, 152, 153) preferring not to be “frightened with too much knowledge” (97) (p.969).

In a minority of cases, patients with lung cancer described information as not forthcoming when they wanted it and, as a consequence, felt ill-informed (94, 99, 122, 147). This was more frequently the case in patients with COPD. Patients often felt poorly informed about their condition and treatment at diagnosis and this continued throughout their disease trajectory (33-46, 74, 76, 78, 81, 108, 123, 127,

130, 133, 137, 154). This could be as fundamental as being given an inhaler without instructions on how to use it (42, 45).

Information could become a source of anxiety in both COPD and lung cancer when it was inconsistent or contradictory (36, 44, 56, 79, 89, 96-98, 109, 110, 122). Patients with lung cancer found the side effects of treatment about which they had not been informed, significantly more distressing than those symptoms about which they had been warned and therefore anticipated (88, 89).

Capacity (primary construct):

We found, in both conditions, capacity could be enhanced and/or, paradoxically, diminished following diagnosis.

Capacity enhanced following diagnosis:

Family and friends (secondary construct):

Patients with lung cancer and COPD repeatedly described family and friends as the main source of support for their treatment workload (37, 49, 55, 58, 66, 67, 73, 74, 76, 79, 80, 87, 108, 125, 130, 132, 147). Informal caregivers, like patients with lung cancer, prioritised the demands of treatment workload over the demands of everyday life and thus put their own life on hold:

Participants and carers described their ...life as inextricably tied to and affected by treatment patterns, appointments, complications and side effects. Additionally, the impact of various test results created a "scan by scan", "treatment cycle by cycle" or "suspended" approach to life, which had an impact not only for the patient but also carers and family. (67) (p.24)

There could be an explicit recognition that this was possible owing to the short disease trajectory in lung cancer (54).

Informal caregivers' participation in the treatment workload, whilst practically onerous, was often seen as an affirmation of the strength of their relationship with the patient (55, 66, 132, 151). This was echoed in many of the COPD studies (36, 73, 79, 80, 130). Indeed, there was a suggestion from some informal caregivers that the demands of the caring role deepened and enhanced their relationship with the patient over the protracted COPD disease trajectory (58, 74). Yet, still more studies demonstrate that informal caregivers felt "compelled" to take on a caring role rather than this being a conscious choice. Their identity imperceptibly and inexorably shifted from family member to caregiver (36, 37, 74, 76, 80, 130, 133, 136). The length of the disease trajectory in COPD meant that the informal caregiver, like the patient, had to balance the demands of treatment workload with the demands of everyday life (36, 74, 76, 130, 133, 136). The studies included repeatedly show that informal caregivers might find this practically limiting and affectively and cognitively demanding (36, 37, 69, 74, 76, 80, 83, 130, 133, 136, 137, 145).

Interestingly, despite the evidence of significant workload encountered by informal caregivers in COPD, it was patients with lung cancer who consistently described their fear of being a "burden" on their caregivers (49, 52, 54, 85, 86, 91, 95, 96, 99, 132, 147). This was less common in the COPD studies (42, 75, 101, 127), perhaps because the gradual development of the caring role over the long disease trajectory meant that the tasks the caregiver took on were not always obvious to the patient.

Health care professionals (secondary construct):

Patients with lung cancer frequently reported the importance of support from empathetic, trusted specialist HCPs in whom they had faith (49, 53, 66, 85-87, 93, 97, 121, 122, 131, 132). Patients with COPD also described positive experiences of interactions with HCPs (125, 129), particularly those with a specialist interest in COPD (57, 78, 80, 103, 106, 109, 120, 127) or those with whom they had relational continuity (80, 109, 125, 129). Patients with COPD described lack of relational continuity with HCPs as making access to, and navigation of, the healthcare system more challenging (81, 109, 111, 129). In a small minority of lung cancer cases, patients had lost confidence in their HCPs (85, 122). This loss of confidence in HCPs appeared more common in COPD (35, 38, 41, 44, 45, 73-76, 109, 113, 123, 126).

Peer support (secondary construct):

Patients with COPD appeared to benefit hugely from peer support (40, 68, 82, 108), which they generally accessed through PR (56, 57, 100-105, 107, 115, 135, 155). Peer support had both psychosocial benefits as patients felt less isolated (56, 100-102, 104, 105, 107, 115, 135) and practical benefits as a means of information-sharing about treatment options (56, 57). In contrast, there appeared to be little formal peer support accessed by patients with lung cancer. Interactions with other patients tended to be impromptu and often transitory (91, 97, 156) perhaps because of the typically short disease trajectory of lung cancer.

Disease trajectory (secondary construct):

Patients with COPD described a process of getting to know their bodies and symptoms over their long disease trajectory and, through a process of trial and error, being able to adapt and normalise treatments into their daily life (35, 37, 42, 68, 73, 103, 114, 150). Patients attending PR reported the importance of support to self-

manage, and education and information about their condition from specialist HCPs (78, 101-106, 115). In contrast, patients with lung cancer described feeling ill-equipped to self-manage symptoms such as breathlessness at home, particularly in the earlier stages of treatment (92). This may be because the short disease trajectory of lung cancer does not allow patients to develop adequate self-management techniques

Capacity diminished following diagnosis:

Stigma (secondary construct):

Stigma occurs when society labels someone ‘tainted’ or ‘spoiled’ on the basis of an attribute that signals their difference to a societally perceived norm (157). Scambler (2008) usefully distinguishes between ‘enacted’ and ‘felt’ stigma (62). ‘Enacted’ stigma is actual discrimination by society against people with stigmatizing conditions. ‘Felt’ stigma is internalized stigma by people with stigmatizing conditions, manifesting itself as shame, guilt or blame or as fear of ‘enacted’ stigma.

In the papers included, patients with lung cancer and COPD frequently reported being considered culpable for their illness through smoking and consequently stigmatized by society (38, 40, 75, 113, 126, 151, 158). Patients with both conditions clearly internalized this stigma, repeatedly describing their diseases as “self-inflicted” (33, 35, 44, 75, 77, 79, 85, 101, 158-160). They experienced ‘felt’ stigma of self-blame, guilt and shame (38, 40, 44, 49, 75, 79, 85, 101, 145, 152, 158, 159). Some patients with COPD described how this internalized stigma led them to believe they do not deserve treatment (40, 101) : “I refused to go to the doctor. I thought it [COPD] was self-inflicted. If it’s self-inflicted, why bother anyone?” (101) (p.314).

Conversely, in the papers included, patients with lung cancer did not describe themselves as undeserving of treatment. Only one patient in one lung cancer study reported having to “endure” the unpleasant side effects of treatment because of his smoking history (147).

Both COPD and lung cancer are not immediately visible to others. Patients reported how fear of ‘enacted’ stigma led them to conceal their illness identity (38, 40, 49, 152). Thus, patients with both conditions attempted to impose a “closed awareness context” (28), concealing their illness from all but a select few. Patients with both conditions also experienced the fear of ‘enacted’ stigma when ‘marked’ as unwell by their treatment (42, 87, 91, 137, 143). Hair loss caused by the side effects of lung cancer treatment is a clear signal of illness as is the ambulatory oxygen carried by some patients with COPD. In both conditions, therefore, the visible side effects of treatment or technologies may disrupt the “closed awareness context” (28) patients have carefully maintained around their illness identity, leading to patients avoiding social situations and, consequently, social isolation (42, 126)

Patients with COPD often described feeling stigmatized by their HCPs (39, 40, 44, 71, 74, 75, 118, 126-128). Patients with COPD and their informal caregivers felt that HCPs believed that patients who had smoked were not entitled to treatment or gave substandard treatment to (ex) smokers (39, 75, 126, 128):

“Well, the care from Father’s doctors was extremely basic and, I felt, on the most part extremely uncaring...The doctors really had an attitude of ‘You were a smoker, you’re dying of lung disease, and what do you want us to do about it’ (36) (p.161).

Consequently, patients were reluctant to access treatment for fear of such enacted stigma (38, 40). Several papers reported the difficulties of accessing treatment for patients who had smoked (36, 75, 126, 128). One study described an extreme example of HCP stigma where the authors argue that patients receiving non-invasive ventilation, an unpleasant treatment for exacerbations of COPD, experienced this as a “punishment” for their “self-inflicted” disease (118).

In contrast, in the studies included, patients with lung cancer did not describe encountering stigmatizing attitudes from HCPs. Only one patient in one study was concerned that their care would be affected because of the links the disease had to smoking (158).

Social isolation (secondary construct):

Self imposed social isolation:

Frequently, patients with lung cancer and COPD experienced social isolation because of their illness (36, 37, 42, 53, 66, 74, 76-80, 82, 96, 101, 102, 111, 114, 126, 127, 133, 136, 139, 143, 145, 156, 161, 162). This might be self-imposed because of embarrassment about visible symptoms (such as breathlessness and cough), medications (such as inhalers) or health technologies (such as oxygen) that mark patients as ill and therefore expose them to the threat of enacted stigma (42, 77, 87, 90, 91, 137, 142, 143). Additionally, in COPD, self-imposed isolation was also used as a self-management technique to avoid exacerbation triggers (such as the risk of infection from crowds) (76, 111).

Involuntary social isolation:

Social isolation might likewise be involuntary in both lung cancer and COPD as friends withdrew and social networks contracted (50, 53, 82, 101, 136, 143, 156).

Patients reported feeling “contagious” (50)(p.734), (136)(p. 145). In both conditions, social isolation was also a result of common psychological comorbidities such as depression, low mood and anxiety following diagnosis leading to avoidance of social situations (53, 78, 79, 82, 101, 102, 156).

Patients with COPD reported that the practical and logistical challenges of the treatment workload itself (for example, the weight of portable oxygen cylinders, the fear of running out of oxygen while waiting for appointments, having complex technologies such as non-invasive ventilation at home) further added to involuntary social isolation (38, 42, 58, 59, 69, 73, 79, 108, 111, 126, 137, 139-141, 143). In COPD, involuntary social isolation also appeared to worsen with disease progression and the consequent relentless deterioration of physical function (37, 74, 80, 82, 127, 139, 161, 162). This clearly extended beyond the patient to affect the informal caregiver as their responsibilities increased with the pathophysiological decline of the patient (36, 37, 74, 76, 80, 133, 136). In the papers included, there were fewer accounts of this from patients with lung cancer, perhaps because of the typically short disease trajectory (96).

Discussion:

Illness as agent; patient as agent:

The overriding discourse evident throughout the lung cancer studies is that of ‘illness as agent’. Patients with lung cancer, informal caregivers and HCPs immediately recognise lung cancer as an existential threat. In order to stave off death, the significant demands of treatment workload become the overriding life priority in what is typically a short illness trajectory. Patients with lung cancer have to undergo a gruelling treatment workload in secondary care, with potentially debilitating

1
2
3 pathophysiological side effects but limited delegated tasks from HCPs. This workload
4
5 is generally well supported by an immediacy of access to healthcare institutions and
6
7 specialist HCPs and a typically clear and structured treatment pathway. Patients with
8
9 lung cancer often regard the practicalities of the treatment workload as a relief from
10
11 the cognitive burden the existential threat of their illness identity has imposed.
12
13 Patients and informal caregivers use the simile of “treatment as hope” and may be
14
15 reluctant to stop treatment, despite potentially devastating side effects.
16
17

18
19 Conversely, the recurrent theme throughout the COPD studies is that of ‘patient as
20
21 agent’. Patients do not recognise or understand their illness and therefore do not
22
23 consider it a terminal disease. Consequently, the demands of treatment workload are
24
25 balanced with the domestic, professional and sentimental demands of the workload
26
27 of everyday life throughout the typically long illness trajectory. Patients with COPD
28
29 are delegated a wide range of highly complex treatment tasks by HCPs to self-
30
31 manage at home. This workload may be made more onerous by difficulties of access
32
33 to, and navigation of, primary and secondary healthcare systems, generalist
34
35 professional gatekeepers who lack understanding of COPD and a fragmented
36
37 treatment pathway that does not meet the needs of home-based self-management.
38
39 Synthesis of patient and informal caregiver accounts demonstrates that poorly
40
41 supported self-management is hard, unrelenting work for patients with COPD and
42
43 their informal caregivers. Patients and their informal caregivers can build up
44
45 strategies over time to self-manage their condition more effectively, particularly when
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47 supported by healthcare provision such as PR. Nonetheless, pathophysiological
48
49 deterioration and increasingly complex management and treatment regimens mean
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51 that the demands of the treatment workload over the long disease trajectory
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53 accumulate. Thus, institutionalized care that temporarily relieves patients and
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informal caregivers of the practical, affective and cognitive workload of self-management may be seen as a welcome respite from self-management. Yet patients with COPD often lack access to such specialist, institutionalized care, especially at the end of life (163, 164)

Social skill, capital and structural resilience:

Patients with lung cancer and COPD are typically able to draw on the support of family and friends which enhances their social skill (the extent to which they are able to secure the co-operation and co-ordination of others) and social capital (their ability to access informational and material resources), bolstering their structural resilience (their potential to absorb adversity) (1). Like patients themselves, informal caregivers of patients with lung cancer recognise cancer's existential threat and prioritise supporting the treatment workload over the demands of everyday life. This support can be a cathartic and life-enhancing process for patients and informal caregivers alike. While this can also apply in COPD, informal caregivers often lack choice in taking on the caregiving role, describing an inexorable process of accumulating responsibility over the long disease trajectory as patients' functional performance deteriorates. In lung cancer, informal caregivers may also lack choice in taking on the caregiving role but the disease trajectory (and thus the caring trajectory) is shorter.

The "weaker ties" (165) of peer support are extremely important in enhancing the social skill and capital of patients with COPD and bolstering structural resilience. In lung cancer, because of its high mortality and short disease trajectory, patients are less likely to need peer support, or indeed, be able to access it as their peers die around them.

Illness related and especially smoking related ‘felt’ and ‘enacted’ stigma degrade the social skill and capital of patients with both conditions. The invisibility of both conditions, unless ‘marked’ by treatment means that patients may attempt to conceal their condition, leading to social isolation. Social isolation is increased by the psychosocial impact of diagnosis and pathophysiological deterioration caused by both illness and the side effects of treatments. Stigma and social isolation and the consequent loss of opportunities to use social skill and access capital, reduces the structural resilience of patients with both conditions.

Strengths and limitations:

This systematic review and qualitative synthesis differs from previous reviews on BoT. BoT has been examined generally across many conditions (2, 12), with capacity considered specifically (3). Other systematic reviews are condition specific: heart failure (8, 10) and stroke (9). Yet more consider treatment burden in multiple chronic conditions: diabetes, chronic kidney disease and heart failure (6) and chronic kidney disease, heart failure and COPD (166). This review, like May et al (166), considers patient and caregiver interactions with health care services in order to characterise treatment burden but identifies primary qualitative papers rather than systematic reviews and meta-syntheses.

To the best of our knowledge, this review is the first to explicitly compare BoT in malignant and non-malignant disease. As such, it offers a novel review which synthesises patient and informal caregiver perspectives on burden of treatment in malignant and non-malignant disease across a range of healthcare systems and settings. It identifies and characterises BoT in lung cancer and COPD through the development of a taxonomy (Table 2). This has important implications both for researchers seeking to understand BoT and for clinicians, as they seek to ameliorate

the impact of treatment on respiratory patients and their informal caregivers. We have made recommendations for clinical practice which can be found in Table 3.

The heterogeneity of the papers included is both a strength and limitation of this synthesis. The heterogeneity of papers means uniformities identified through the taxonomy should facilitate the development of an explanatory model of burden of treatment (167). However, the taxonomy has been developed from descriptions of patient experience taken *out of context*. It describes the generalities of patient experience across multiple healthcare systems and settings, rather than considering factors such as socioeconomic status and the attributes of healthcare systems that have been shown to be important in the consideration of BoT (1). Furthermore, qualitative research is, necessarily, interpretative and therefore the data analysed, whilst ostensibly from primary sources, are seen through the multiplicity of theoretical lenses chosen by the studies' authors and their varying epistemological and ontological stances. Finally, this paper itself uses an interpretative framework for synthesis and therefore results are refracted through the authors' own lenses.

We limited our search to publications between January 2006- December 2015 as we intended to identify burden of treatment in COPD and lung cancer with the aim of informing *current* health care practice and policy. In their discussion of the methodological challenges of reviewing patient experience of treatment burden in stroke, Gallacher et al (7) highlight how the management of chronic disease has changed dramatically in recent years. We believed it was important, therefore, that pertinent (and thus more recent) literature was identified and reviewed to ensure that patient experience of treatment burden was based on current rather than historical healthcare practices. The systematic review took some time to undertake and write up, hence publications after December 2015 are not included which is a limitation.

We excluded studies that were not in peer reviewed journals (i.e. grey literature) and studies that are not in the English language because of resource constraints which could be regarded as a limitation.

What is not in the literature:

The studies identified focus almost exclusively on the index conditions of lung cancer and COPD. Studies focus on lung cancer or COPD, whereas many patients may have both lung cancer and COPD (168). They do not discuss the issue of multimorbidity which is common in both conditions (169) (170) and is likely to have a significant impact on BoT (4).

Conclusions:

This interpretative synthesis of qualitative literature on patient/informal caregiver interactions with healthcare in lung cancer and COPD demonstrates that the workload of treatment may be very different in each condition. The socio-cultural status of cancer as one of the most feared of all diseases (60, 61) means that ‘illness is agent’. Thus, lung cancer patients are required to subordinate the demands of everyday life to the demands of the treatment workload. Patients have little choice but to follow a structured treatment pathway, in healthcare systems that generally meet the needs of their typically short diseases trajectory. Conversely, in COPD, patients are expected to exert agency over their own condition, “empowered” to self-manage, integrating the demands of the treatment workload into their everyday life. Patients have to identify their own treatment pathway, navigating between institutions, in healthcare systems that are not set up to meet the needs of their uncertain and often lengthy disease trajectory. The differences in the treatment workload of lung cancer and COPD identified by this synthesis resonate with other

qualitative studies comparing cancer with other chronic conditions (predominantly heart failure but also COPD and motor neurone disease) (61, 171, 172).

Despite the differences of the treatment workload between conditions, this interpretative synthesis has demonstrated the importance of the personal and collective capacity available to patients and their informal caregivers in both conditions, suggesting that a workload which exceeds capacity is likely to be a primary driver of treatment burden.

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Table 1: Inclusion/exclusion criteria for systematic review

Inclusion criteria	Exclusion criteria
Participants: aged >18, diagnosed with lung cancer or COPD, or their informal caregivers	Reports: of treatment effectiveness, for example RCTs; reports of healthcare provision which are not focused on patients' or informal caregivers' experiences; qualitative studies which focus only on professional experience, or report secondary analyses, or review or synthesise data; editorials, notes, letters and case reports; protocols of qualitative studies, mixed methods studies
Reports: results of primary qualitative studies of patients' or informal caregivers' experiences of interactions with health and social care services published in peer reviewed journals	Insufficient data to answer research question
Settings: healthcare systems in Europe (excluding Turkey), North America and Australia	
Date of publication: between 1 January 2006 and 31 December 2015	
Language: English	

Table 2. Taxonomy of treatment burden in lung cancer and COPD.

PRIMARY CONSTRUCT	SECONDARY CONSTRUCT	LUNG CANCER	REFERENCES	COPD	REFERENCES
Workload (the affective, cognitive, informational, material and relational tasks delegated to patients/caregivers)	Diagnosis/illness identity	Diagnosis as shock	47-55	Diagnosis imperceptible	33-46
		Obvious illness identity with socio-cultural resonance (therefore understood by patient/informal caregiver/HCP)	50, 53, 64	Unclear illness identity, without socio-cultural resonance (therefore poorly understood by patient/informal caregiver/HCP)	33-35, 37, 39, 42, 43, 45, 56-59
		Short disease trajectory (clear to patient and informal caregiver)	50, 53, 64	Long and uncertain disease trajectory (unclear to patient and informal caregiver)	33-35, 37, 39, 42, 43, 45, 56-59
	Attitude towards treatment	Demands of treatment workload as overriding life priority (for both patient and informal caregiver)	64-67	Demands of treatment workload balanced with domestic/professional/sentimental demands of everyday life (for both patient and informal caregiver)	35, 43, 57, 59, 68-73
		Practical demands of treatment workload as a relief from the existential threat of cancer	51, 53, 86, 93	Practical demands of treatment workload as hard work	33, 37, 39, 42, 70, 72, 74-84
		Treatment as hope	49, 51, 64, 86, 87, 91, 94, 95	Institutionalized care as respite from unrelenting	57, 58, 84, 104, 109-119

		Sense of 'limbo' once treatment completed	48, 66, 96-98	demands of self-management	
		Reluctance to stop treatment despite debilitating pathophysiological side effects	86		
		Treatment for family rather than for patient	67, 87, 99		
	Treatment options	Lack of options: treatment or death	67, 91, 93, 97, 121	Lack of treatment options (lack of information or feeling that 'nothing can be done' from HCPs)	35, 57, 70, 113, 123
		Decision to cede control over choice of treatment options to trusted HCPs	86, 93, 97, 99, 121, 122		
	Access to/navigation of healthcare system/Institutions	Immediacy of access to healthcare	49, 67, 85, 121, 131, 132	Difficulties with access to healthcare	44, 45, 58, 78, 109, 112, 113, 116, 124, 126, 129
		Specialist HCPs with specific knowledge of lung cancer	49, 67, 85, 121, 131, 132	Generalist HCPs who lack specific knowledge of COPD	44, 45, 58, 78, 109, 112, 113, 116, 124, 126, 129
		Structured treatment pathway	49, 53, 66, 67, 85, 121, 131, 132	Fragmented treatment pathway	34, 37, 42, 44, 58, 73, 74, 76, 103, 108, 109, 116, 120, 126, 127, 129
	Practical workload of treatment	Specialist treatment workload in secondary care with debilitating pathophysiological side effects	52, 91, 134	Multiple appointments for treatment in primary, secondary care and in the community	73, 101, 108, 120, 123, 125, 133, 135
		Limited delegated tasks	48, 50, 52, 53,	Significant workload of	33, 35, 37, 42,

		from HCPs	65-67, 86, 89, 91, 93, 97-99, 121, 131, 146	delegated treatment tasks at home from HCPs	45, 58, 59, 68, 69, 72-76, 79, 80, 83, 103, 106, 108, 109, 114, 126, 127, 129, 130, 133, 136-145
	Informational workload of treatment	Generally high quality information provided in written form and from specialist HCPs	64, 67, 85, 93, 97-99, 121, 132, 147, 148, 151	Patients typically poorly informed about condition from diagnosis to death adding to treatment workload	33-46, 74, 76, 78, 81, 108, 123, 127, 130, 133, 137, 154
		Lack of information as a deliberate choice on the part of patients – a tactic for maintaining hope in the face of a poor prognosis	48, 51, 64, 66, 97, 99, 121, 122, 152, 153	Conflicting/contradictory information adds to patient/informal caregiver distress	36, 44, 56, 79, 109, 110,
		Conflicting/contradictory information adds to patient/informal caregiver distress	89, 96-98, 122		
Capacity (the affective, cognitive, informational, material and relational resources available to be mobilized by patients/caregivers) - Enhanced by	Family and friends	Family and friends are seen as the main source of support post diagnosis (but fear of being a 'burden' on family)	49, 55, 66, 67, 87, 132, 147 'Burden' : 49, 52, 54, 85, 86, 91, 95, 96, 99, 132, 147	Family and friends are seen as the main source of support post diagnosis	37, 58, 73, 74, 76, 79, 80, 108, 125, 130
		Family and friends are able to prioritise	54	Family and friends have to balance the	36, 74, 76, 130, 133, 136

diagnosis		supporting the patient through their treatment workload owing to the short disease trajectory and the recognition of the patient's likely imminent death		demands of the treatment workload with the demands of everyday life owing to the long and uncertain disease trajectory	
		Support for the patient's treatment workload seen as an affirmation of the strength of the patient/family member relationship in the face of imminent death	55, 66, 132, 151	Support for the patient's treatment workload may be seen as an affirmation of the strength of the patient/family member relationship	36, 58, 73, 74, 79, 80, 130
				Caregivers feel compelled to take on a care-giving role over the long duration of the disease trajectory	36, 37, 74, 76, 80, 130, 133, 136
	Healthcare professionals	Importance of support from empathetic, trusted HCPs in whom patients have faith	49, 53, 66, 85-87, 93, 97, 121, 122, 131, 132	Importance of support from trusted HCPs, especially those with specialist knowledge of COPD	57, 78, 80, 103, 106, 109, 120, 125, 127, 129
		Less commonly, loss of faith in HCPs	85, 122	Importance of relational continuity with HCPs making access to and navigation of the healthcare system and its institutions easier	80, 81, 109, 111, 125, 129
				Loss of faith in HCPs	35, 38, 41, 44, 45, 73-76,

					109, 113, 123, 126
	Peer support	Little peer support available for patients with lung cancer. What is available appears impromptu and transitory	91, 97, 156	Peer support is an important resource and is generally accessed through pulmonary rehabilitation	40, 68, 82, 108 PR: 56, 57, 100-105, 107, 115, 135, 155
				Shared experiences with peers reduces isolation	56, 100-102, 104, 105, 107, 115, 135
				Peer support is used as a resource for information sharing	56, 57
	Disease trajectory	Short disease trajectory: ill equipped to self manage symptoms at home	92	Long disease trajectory: get to know their bodies and symptoms, through trial and error	35, 37, 42, 68, 73, 103, 114, 150
Capacity (the affective, cognitive, informational, material and relational resources available to be mobilized by patients/caregivers) - Diminished by diagnosis	Stigma	Patients are considered culpable for their illness and stigmatized by society	151, 158	Patients are considered culpable for their illness and stigmatized by society	38, 40, 75, 113, 126
		Patients consider themselves culpable for their illness: a "self-inflicted" disease	85, 159, 160	Patients consider themselves culpable for their illness: a "self-inflicted" disease	33, 35, 44, 75, 77, 79, 101, 161
		Patients experience 'felt' stigma of blame, guilt and shame	49, 85, 152, 158, 159	Patients experience 'felt' stigma of blame, guilt and shame	38, 40, 44, 75, 79, 101, 145
		Patients attempt to conceal their condition owing to fear of 'enacted' stigma leading to social	49, 152	Patients attempt to conceal their condition owing to fear of 'enacted' stigma leading to social	38, 40

		isolation		isolation	
		Patients feel 'marked' by visible treatment leading to social isolation	87, 91	Patients feel 'marked' by visible treatment leading to social isolation	42, 126, 137, 143
				Patients internalize stigma, considering themselves undeserving of treatment	40, 101
				Patients experience 'enacted' stigma from HCPs, making access to treatment challenging	36, 38, 39, 40, 44, 71, 74, 75, 118, 126-128
	Social isolation (Self-imposed)	Embarrassment about symptoms, medications and treatment technologies which mark the patient as ill leading to fear of 'enacted' stigma	87, 90, 91	Embarrassment about symptoms, medications and treatment technologies which mark the patient as ill leading to fear of 'enacted' stigma	42, 77, 137, 142, 143
				Exacerbation triggers – leads to avoidance of social situations	76, 111
	Social isolation (Involuntary)	Illness as contagious: social networks contract as friends withdraw	50, 53, 156	Illness as contagious: social networks contract as friends withdraw. Isolation worsens with disease progression and deterioration of physical function	82, 101, 136, 143 Deterioration: 37, 74, 80, 82, 127, 139, 161, 162
		Psychological co-morbidities	53, 156	Logistical difficulties of	38, 42, 58, 59,

		lead to avoidance of social situations		treatment workload limits patient to home	69, 73, 79, 108, 111, 126, 137, 139-141, 143
				Social isolation extends beyond patient to affect informal caregiver	36, 37, 74, 76, 80, 133, 136
				Psychological co-morbidities lead to avoidance of social situations	78, 79, 82, 101, 102

Table 3: Recommendations for clinical practice

RECOMMENDATIONS FOR CLINICAL PRACTICE:
Patients living with respiratory disease and their informal caregivers may experience treatment as hard work. Equally, patients and caregivers may see treatment as ‘hope’ and therefore be reluctant to stop.
Patients’ capacity to undertake the treatment workload may be enhanced and/or diminished by diagnosis. Consideration should be given to the volume of treatment workload delegated to the patient/informal caregiver and their capacity undertake this workload. Clinicians could use the taxonomy (table 2) to aid and support consideration and discussion of workload and capacity.

Legend:

Figure 1: PRISMA flowchart for COPD articles

Figure 2: PRISMA flowchart for lung cancer articles

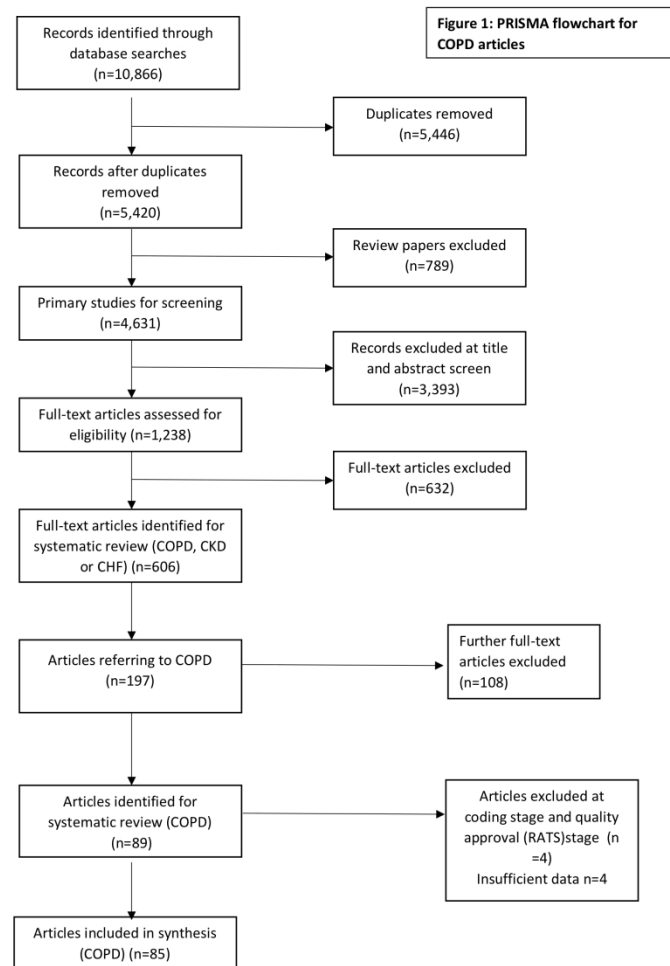


Figure 1: PRISMA flowchart for COPD articles

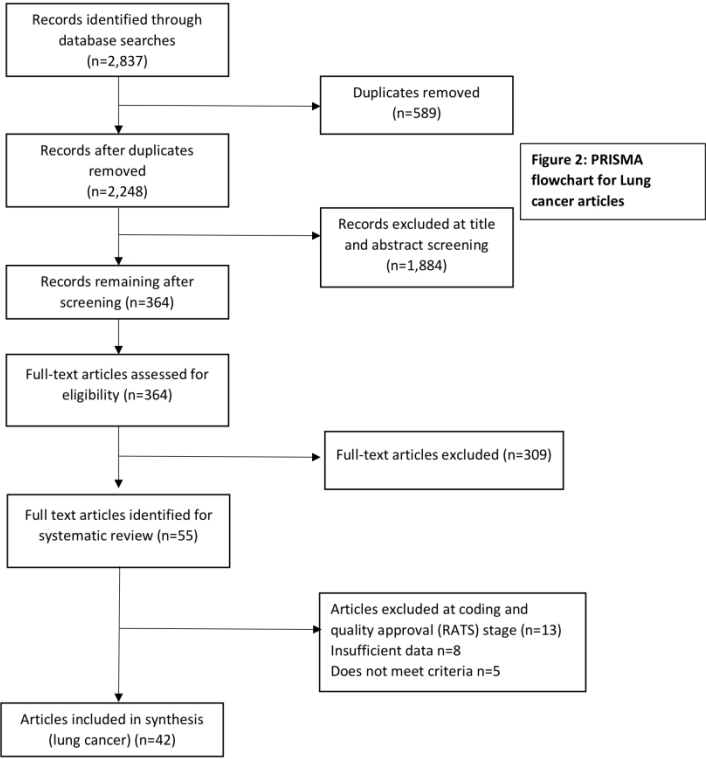


Figure 2: PRISMA flowchart for lung cancer articles

Appendix 1: MEDLINE SEARCH STRATEGY. OVID INTERFACE.

CHF/CKD/COPD:

- 1 Heart Failure/
- 2 heart failure, diastolic/ or heart failure, systolic/
- 3 ((heart\$1 or cardiac or cardial or myocardial) adj3 failure\$1).ti,ab,kf.
- 4 ((heart\$1 or cardiac or cardial or myocardial) adj3 decompensat\$).ti,ab,kf.
- 5 ((heart\$1 or cardiac or cardial or myocardial) adj3 incompetenc\$).ti,ab,kf.
- 6 ((heart\$1 or cardiac or cardial or myocardial) adj3 insufficienc\$).ti,ab,kf.
- 7 ((heart\$1 or cardiac or cardial or myocardial) adj3 (standstill or stand-still)).ti,ab,kf.
- 8 (CHF or CHF\$).ti,ab,kf.
- 9 or/1-8
- 10 exp Renal Insufficiency, Chronic/
- 11 Renal Insufficiency/
- 12 exp Renal Replacement Therapy/
- 13 Hemodialysis Units, Hospital/
- 14 (chronic kidney or chronic renal or chronic nephropath\$).ti,ab,kf.
- 15 (kidney failure\$1 or renal failure\$1).ti,ab,kf.
- 16 (renal insufficienc\$ or kidney insufficienc\$).ti,ab,kf.
- 17 (dialysis or predialysis).ti,ab,kf.
- 18 (hemodialysis or haemodialysis).ti,ab,kf.
- 19 (hemofiltration or haemofiltration).ti,ab,kf.
- 20 (hemodiafiltration or haemodiafiltration).ti,ab,kf.
- 21 (end-stage renal or end-stage kidney or endstage renal or endstage kidney).ti,ab,kf.
- 22 (stage 5 and (renal disease\$1 or kidney disease\$1)).ti,ab,kf.
- 23 (kidney transplant\$ or renal transplant\$ or kidney graft\$ or renal graft\$ or kidney replacement\$1 or renal replacement\$1).ti,ab,kf.
- 24 (CKF or CKD or CRF or CRD).ti,ab,kf.
- 25 (ESKD or ESRD or ESKF or ESRF).ti,ab,kf.
- 26 (CAPD or CCPD or APD).ti,ab,kf.
- 27 or/10-26
- 28 exp Pulmonary Disease, Chronic Obstructive/
- 29 (obstruct\$ adj3 (pulmonary or lung\$1 or airway\$1 or airflow\$1 or bronch\$ or respirat\$)).ti,ab,kf.
- 30 (chronic\$ adj3 bronchiti\$).ti,ab,kf.
- 31 emphysem\$.ti,ab,kf.
- 32 (COPD or COAD or COBD or AECB).ti,ab,kf.
- 33 or/28-32
- 34 9 or 27 or 33
- 35 exp qualitative research/
- 36 qualitativ\$.ti,ab,kf.
- 37 interviews as topic/
- 38 interview\$.ti,ab,kf.
- 39 focus groups/
- 40 focus group\$1.ti,ab,kf.
- 41 grounded theory/ or (grounded theor\$ or grounded study or grounded studies or grounded research or grounded analys\$).ti,ab,kf.
- 42 phenomenol\$.ti,ab,kf.
- 43 (ethnograph\$ or ethnonurs\$ or ethno-graph\$ or ethno-nurs\$).ti,ab,kf.

44 (story or stories or storytelling or narrative\$1 or narration\$1).ti,ab,kf.
 45 (open-ended or open question\$ or text\$).ti,ab,kf.
 46 Narration/ or personal narratives/ or personal narratives as topic/
 47 (discourse\$ analys\$ or discours\$ analys\$).ti,ab,kf.
 48 content\$ analys\$.ti,ab,kf.
 49 ethnological.ti,ab,kf.
 50 purposive sampl\$.ti,ab,kf.
 51 (constant comparative or constant comparison\$1).ti,ab,kf.
 52 theoretical sampl\$.ti,ab,kf.
 53 (theme\$ or thematic\$).ti,ab,kf.
 54 (emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$).ti,ab,kf.
 55 data saturat\$.ti,ab,kf.
 56 participant observ\$.ti,ab,kf.
 57 exp Humanism/ or (humanistic\$ or existential\$ or experiential\$ or
 paradigm\$).ti,ab,kf.
 58 Postmodernism/ or (social construct\$ or postmodern\$ or post-modern\$ or
 poststructural\$ or post-structural\$ or feminis\$ or constructivis\$).ti,ab,kf.
 59 (action research or cooperative inquir\$ or co-operative inquir\$).ti,ab,kf.
 60 human science.ti,ab,kf.
 61 biographical method\$.ti,ab,kf.
 62 life world.ti,ab,kf.
 63 theoretical saturation.ti,ab,kf.
 64 group discussion\$1.ti,ab,kf.
 65 direct observation\$.ti,ab,kf.
 66 mixed method\$.ti,ab,kf.
 67 (observational method\$ or observational approach\$).ti,ab,kf.
 68 key informant\$1.ti,ab,kf.
 69 (field study or field studies or field research\$ or field work\$ or fieldwork\$).ti,ab,kf.
 70 (semi-structured or semistructured or unstructured or un-structured or informal or
 in-depth or indepth).ti,ab,kf.
 71 "face-to-face".ti,ab,kf.
 72 ((guide or structured) adj5 (discussion\$1 or questionnaire\$1)).ti,ab,kf.
 73 (heidegger\$ or colaizzi\$ or speigelberg\$ or van manen\$ or van kaam\$ or merleau
 ponty\$ or husserl\$ or giorgi\$ or foucault\$ or corbin\$ or glaser\$).ti,ab,kf.
 74 or/35-73
 75 Consumer Behavior/
 76 attitude/ or exp attitude to health/ or Attitude to Death/
 77 personal satisfaction/
 78 exp Emotions/
 79 Stress, psychological/
 80 exp Patients/px
 81 Caregivers/px
 82 professional-patient relations/ or nurse-patient relations/ or physician-patient
 relations/
 83 professional-family relations/
 84 Empathy/
 85 Feedback/
 86 ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or
 caregiver\$1 or care-giver\$ or family\$1 or families) and (experient\$ or perspective\$1
 or perception\$1 or opinion\$1 or account or accounts or attitude\$1 or view or views

or viewpoint\$1 or satisf\$ or unsatisf\$ or dissatisf\$ or disatisf\$ or belief\$1 or believ\$)).ti.

87 ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or care-giver\$ or family\$1 or families) adj3 (experient\$ or perspective\$1 or perception\$1 or opinion\$1 or account or accounts or attitude\$1 or view or views or viewpoint\$1 or satisf\$ or unsatisf\$ or dissatisf\$ or disatisf\$ or belief\$1 or believ\$)).ab,kf.

88 ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or care-giver\$ or family\$1 or families) and (emotion\$ or feeling\$1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet\$ or anxious\$ or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat\$ or stress\$ or distress\$ or embarrass\$ or empath\$ or accept\$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother\$ or unbother\$ or pleased or displeased\$ or concern\$ or burden\$ or hassl\$ or convenien\$ or inconvenien\$ or confus\$ or hope or hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or confiden\$ or unconfiden\$)).ti.

89 ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or care-giver\$ or family\$1 or families) adj3 (emotion\$ or feeling\$1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet\$ or anxious\$ or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat\$ or stress\$ or distress\$ or embarrass\$ or empath\$ or accept\$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother\$ or unbother\$ or pleased or displeased\$ or concern\$ or burden\$ or hassl\$ or convenien\$ or inconvenien\$ or confus\$ or hope or hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or confiden\$ or unconfiden\$)).ab,kf.

90 (life experience\$1 or lived experience\$1 or actual experience\$1 or real experience\$1).ti,ab,kf.

91 or/75-90

92 34 and 74 and 91

93 ((heart\$1 or cardiac or cardial or myocardial) adj3 (failure\$1 or decompensation or incompetenc\$ or insufficienc\$ or standstill or stand-still)).ti.

94 (CHF or CHF\$).ti.

95 (kidney or renal or nephropath\$ or dialysis or predialysis or hemodialysis or haemodialysis or hemofiltration or haemofiltration or hemodiafiltration or haemodiafiltration or CKF or CKD or CRF or CRD or ESKD or ESRD or ESKF or ESRF or CAPD or CCPD or APD).ti.

96 (obstruct\$ adj3 (pulmonary or lung\$1 or airway\$1 or airflow\$1 or bronch\$ or respirat\$)).ti.

97 (chronic\$ adj3 bronchiti\$).ti.

98 emphysem\$.ti.

99 (COPD or COAD or COBD or AECB).ti.

100 or/93-99

101 qualitativ\$.ti. or qualitative research/

102 ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or care-giver\$ or family\$1 or families) and experiences).ti.

103 ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or care-giver\$ or family\$1 or families) adj2 experienc\$).ti.

104 100 and (101 or 102 or 103)

105 92 or 104

106 exp animals/ not humans/

107 (news or comment or editorial or letter or case reports or randomized controlled trial).pt.

108 case report.ti.

109 105 not (106 or 107 or 108)

110 limit 109 to (english language and yr="2006 -Current")

111 remove duplicates from 110

Lung cancer:

1. exp Lung Neoplasms/

2. Carcinoma, Non-Small-Cell Lung/

3. Small Cell Lung Carcinoma/

4. (lung adj2 cancer\$).ti,ab,kf.

5. 1 or 2 or 3 or 4

6. exp Qualitative Research/

7. qualitativ\$.ti,ab,kf.

8. Interviews as Topic/

9. interview\$.ti,ab,kf.

10. Focus Groups/

11. focus group\$1.ti,ab,kf.

12. Grounded Theory/

13. (grounded theor\$ or grounded study or grounded studies or grounded research or grounded analys\$).ti,ab,kf.

14. phenomenol\$.ti,ab,kf.

15. (ethnograph\$ or ethnonurs\$ or ethno-graph\$ or ethno-nurs\$).ti,ab,kf.

16. (story or stories or storytelling or narrative\$1).ti,ab,kf.

17. (open-ended or open question\$ or text\$).ti,ab,kf.

18. Narration/

19. Personal Narratives/

20. Personal Narratives as Topic/

21. (discourse\$ analys\$ or discours\$ analys\$).ti,ab,kf.

22. content\$ analys\$.ti,ab,kf.

23. ethnological.ti,ab,kf.

24. Purposive sampl\$.ti,ab,kf.

25. (constant comparative or constant comparison\$1).ti,ab,kf.

26. theoretical sampl\$.ti,ab,kf.

27. (theme\$ or thematic\$).ti,ab,kf.

28. (emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$).ti,ab,kf.

29. data saturat\$.ti,ab,kf.

30. participant observ\$.ti,ab,kf.

31. exp Humanism/
32. (humanistic\$ or existential\$ or experiential\$ or paradigm\$).ti,ab,kf.
33. Postmodernism/
34. (social construct\$ or postmodern\$ or post-modern\$ or poststructural\$ or post-structural\$ or feminis\$ or constructivis\$).ti,ab,kf.
35. (action research or cooperative inquir\$ or co-operative inquir\$).ti,ab,kf.
36. human science.ti,ab,kf.
37. biographical methods\$.ti,ab,kf.
38. life world.ti,ab,kf.
39. theoretical saturation.ti,ab,kf.
40. mixed method\$.ti,ab,kf.
41. (observational method\$ or observational approach\$).ti,ab,kf.
42. key informant\$1.ti,ab,kf.
43. (field study or field studies or field research\$ or field work\$ or fieldwork\$).ti,ab,kf.
44. (semi-structured or semistructured or unstructured or un-structured or informal or in-depth or indepth).ti,ab,kf.
45. "face-to-face".ti,ab,kf.
46. ((guide or structured) adj5 (discussion\$1 or questionnaire\$1)).ti,ab,kf.
47. (heidegger\$ or colaizzi\$ or speigelberg\$ or van manen\$ or van kaam\$ or merleau ponty\$ or husserl\$ or giorgi\$ or foucault\$ or corbin\$ or glaser\$).ti,ab,kf.
48. 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47
49. Consumer Behavior/
50. Attitude/
51. exp Attitude to Health/
52. Attitude to Death/
53. Personal Satisfaction/
54. exp Emotions/
55. Stress, Psychological/
56. exp Patients/px [Psychology]
57. Caregivers/px [Psychology]
58. Professional-Patient Relations/
59. Nurse-Patient Relations/
60. Physician-Patient Relations/
61. Professional-Family Relations/
62. Empathy/
63. Feedback/
64. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or family\$1 or families) and (experient\$ or perspective\$1 or perception\$1 or opinion\$1 or account or accounts or attitude\$1 or view or views or

viewpoint\$1 or satisf\$ or unsatisf\$ or dissatisf\$ or disatisf\$ or belief\$1 or believ\$)).ti.

65. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or family\$1 or families) adj3 (experient\$ or perspective\$1 or perception\$1 or opinion\$1 or account or accounts or attitude\$1 or view or views or viewpoint\$1 or satisf\$ or unsatisf\$ or dissatisf\$ or disatisf\$ or belief\$1 or believ\$)).ab,kf.

66. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or family\$1 or families) and (emotion\$ or feeling\$1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet\$ or anxious\$ or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat\$ or stress\$ or distress\$ or embarrass\$ or empath\$ or accept\$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother\$ or unbother\$ or pleased or displeased\$ or concern\$ or burden\$ or hassl\$ or convenien\$ or inconvenien\$ or confus\$ or hope or hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or confiden\$ or unconfiden\$)).ti.

67. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or care-giver\$ or family\$1 or families) adj3 (emotion\$ or feeling\$1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet\$ or anxious\$ or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat\$ or stress\$ or distress\$ or embarrass\$ or empath\$ or accept\$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother\$ or unbother\$ or pleased or displeased\$ or concern\$ or burden\$ or hassl\$ or convenien\$ or inconvenien\$ or confus\$ or hope or hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or confiden\$ or unconfiden\$)).ab,kf.

68. (life experience\$1 or lived experience\$1 or actual experience\$1 or real experience\$1).ti,ab,kf.

69. 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68

70. 5 and 48 and 69

71. qualitativ\$.ti.

72. Qualitative Research/

73. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or care-giver\$ or family\$1 or families) and experiences).ti.

74. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or care-giver\$ or family\$1 or families) adj2 experientc\$).ti.

75. 71 or 72 or 73 or 74

76. 5 and 75

77. 70 or 76

78. exp animals/ not humans/

79. (news or comment or editorial or letter or case reports or randomized controlled trial).pt.

80. case-report.ti.

81. 77 not (78 or 79 or 80)

82. limit 81 to (english language and yr="2006 -Current")

For peer review only

Appendix 2. Quality assessment tool (modified RATS)

Reference number/ Reviewer initials	Criteria	Detail	Yes/No
	Relevance	<ul style="list-style-type: none">• Is the research question clearly stated?• Is the question generated from an analysis of the literature?	
	Appropriateness of method	<ul style="list-style-type: none">• Is the qualitative method(s) stated most effective way of addressing the research question?• Is it stated why this method was used?	
	Transparency of research procedures	<ul style="list-style-type: none">• Is the sampling procedure explained?• Are the criteria for the selection of participants stated?• Was the collection of data systematic and comprehensive?• Is the role of the researchers addressed?• Are ethical issues addressed?	
	Soundness of interpretive approach Presentation of findings and common features of poor research	<ul style="list-style-type: none">• Is the analytical approach a reasonable approach and judged to be appropriate for the study?• Are the interpretations clearly outlined and supported by empirical evidence?• Were the interpretations checked?• Are the findings embedded in a theoretical or conceptual framework?• Is the way that the results add to existing knowledge stated?• Are limitations stated?• Is the article well written?• Is there an overuse of jargon?• Do the interpretations seem appropriate? Are they self-evident?• Is there an adequate discussion of consent – thin detail often indicates poor ethics.	

Appendix 3: full characteristics of included studies

COPD

Study	Year	Country	Qualitative method	Index condition	Setting	How sampled?	Sample	Age of sample	Gender of sample	How data analysed?	Study details
Adams et al #157	2006	UK, Netherlands, Denmark	Interviews	COPD	Community	Convenience	23 patients	38-84	16M, 7F	Descriptive (thematic analysis)	To explore the notion of COPD exacerbations from the viewpoint of patients who had recently suffered an exacerbation.
Arnold, E. #165	2011	UK	Interviews	COPD	Community	Purposive	27 patients	54-85	14M, 13F	Theory building (grounded theory)	To obtain in-depth information about perceptions and use of prescribed ambulatory oxygen systems from patients with COPD to inform ambulatory oxygen design, prescription and management.
Arnold, E. #166	2006	UK	Interviews	COPD	Pulmonary rehabilitation (hospital based)	Participants screened against eligibility criteria. All eligible patients invited to participate. Participants recruited until no new themes emerged.	20 patients	45-85	9M, 11F	Theory building (grounded theory)	To explore the experiences of COPD patients invited to join a pulmonary rehabilitation programme.
Boyle, Anne H.#9	2009	USA	Interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	10 wives	57-71	10F	Theory informed (phenomenological-hermeneutic approach)	To describe and understand meaning of experience of living with a spouse who has COPD

Caress, A.#170	2010	UK	Interviews	COPD	Acute hospital	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	14 patients, 12 family members	Patients = 60-80. Family members not stated	Patients = 8M, 6F. Family members = 3M, 9F	Descriptive (content analysis)	To generate in-depth insights into patients' and family members' understanding of the causation, progression and prevention of COPD and the role of health promotion with this population
Clancy, Karen #13	2009	UK	Serial interviews	COPD	Acute hospital	Participants screened against eligibility criteria. Those eligible who agreed to participate included. Informal care-givers nominated by patients.	9 patients, 7 care-givers	Patients = 57-78. Care-givers = 50-78	Patients = 6M, 3F. Care-givers = 2M, 5F	Theory informed (phenomenological-hermeneutic approach)	To explore the existential experiences of patients with COPD who had been prescribed long-term oxygen therapy and their carers
Clarke, A #14	2010	UK	Interviews	COPD	Community	Purposive (maximum variation)	23 patients	50-80	14M, 9F	Theory building (grounded theory)	To explore patients' views of an early supported discharge service for COPD
Cooke, M #15	2012	UK	Focus groups	COPD	Community	Purposive	8 HCPs, 30 patients, 2 care-givers	Patients = 48-73. Care-givers and HCPs not stated	Patients = 16M, 15F. Care-givers = 2F. HCPs not stated	Descriptive (thematic analysis)	To define, compare and order 'assessed needs and defined outcomes' of professional providers of COPD services with patients' 'prioritised needs and defined outcomes' and relate these to service provision

Curry, R. #172	2006	UK	Interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	11 patients	Not stated	Not stated	Descriptive (thematic framework approach)	To explore patients' views of introduction of a new nurse-led urgent care team (UCT) for patients with COPD
Dickenson, J.#19	2009	UK	Interviews	COPD	Community	Participants screened against eligibility criteria.	12 patients	Not stated	Not stated	Descriptive (framework approach)	To explore the COPD patient's perception of their dietary habits and nutritional status and to identify their perceptions of dietary health and its impact on general quality of life.
Ehrlich, Carolyn #22	2010	Australia	Interviews	COPD	Community	Theoretical sampling	9 patients	56-77	4M, 5F	Theory building (grounded theory)	To report how people with COPD gather, interpret and apply health affecting information
Ek, K.#23	2014	Sweden	Interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible, who agreed to participate included.	13 family members	Not stated	7M, 6F	Descriptive (content analysis)	To retrospectively describe the final year of life for patients with advanced COPD with a focus on death and dying from the perspective of relatives.
Ek, K.#24	2011	Sweden	Serial interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	4 patients	66-75	1M, 3F	Theory informed (phenomenological-hermeneutic approach)	To describe the experience of living with advanced COPD and long-term oxygen therapy when living alone

Ek, K.#25	2008	Sweden	Interviews	COPD	Hospital	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	8 patients	48-79	3M, 5F	Theory informed (phenomenological approach)	To describe the essential structure of the lived experience of living with severe COPD during the palliative phase of the disease
Ek, K.#26	2011	Sweden	Serial interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	4 couples (4 patients, 4 spouses)	67-74	4M, 4F	Theory informed (phenomenological-hermeneutic approach)	To examine couples' experiences of living together when one partner has advanced COPD
Ellison, L.#27	2012	UK	Interviews	COPD	Community	Convenience and purposive	14 patients	49-79	7M, 7F	Descriptive (constant comparison and framework approach)	To understand the mental health needs of people living with COPD
Fischer, M. J #31	2007	Netherlands	Interviews	COPD	Pulmonary rehabilitation (outpatient)	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	12 patients	34-77	8M, 4F	Theory informed (interpretative phenomenological analysis)	To examine patients' pre-treatment beliefs and goals regarding pulmonary rehabilitation
Fraser, D. D.#34	2006	USA	Interviews	COPD	Community	Purposive	10 patients	59-86	5M, 5F	Theory informed (phenomenological-hermeneutic approach)	To understand how COPD affects the lives of patients.
Gale, N. K.#36	2015	UK	Interviews	COPD	Community	Purposive	20 patients, 4 carers, 15 HCPs	Patients = 52-83. Carers not stated. HCPs = 26-54	Patients = M = 8, F = 12. Carers and HCPs not stated.	Theory building (grounded theory)	To explore experiences of domiciliary non-invasive ventilation in COPD, to understand decision-making processes and improve future palliative care

Goodridge, D #41	2011	Canada	Interviews	COPD and bronchiectasis	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	7 patients	57-88	2M, 5F	Descriptive (interpretive description)	To explore the impact of living with advanced chronic respiratory illness in a rural area
Gullick, J #45	2008	Australia	Serial Interviews	COPD	Community	Convenience	15 patients, 14 family members	Patients = 55-77. Family members = 29-82	Patients = 9M, 6F. Family members not stated	Theory informed (phenomenological-hermeneutic approach)	To explore the experience of the person who lives within a body with COPD
Guo, S.E. #161	2014	Canada	Interviews and focus groups	COPD	Pulmonary rehabilitation (outpatient)	Patients screened against eligibility criteria. Those eligible who agreed to participate included. HCPs sampled purposively.	25 patients, 7 HCPs	Patients = 53-84. HCPs not stated.	Patients = 13M, 12F. HCPs not stated.	Descriptive (thematic analysis)	To describe the experiences of patients who are in a pulmonary rehabilitation (PR) programme and explore the perceptions of patients and HCPs about what improves effective PR
Gysels #48	2008	UK	Interviews and participant observation	COPD	Community and outpatient clinics	Purposive	18 patients	52-78	7M, 11F	Theory building (grounded theory)	To explore the experience of breathlessness in patients with COPD through patients' accounts of their interactions with services
Gysels #178	2010	UK	Interviews and participant observation	COPD	Community and outpatient clinics	Purposive	18 patients	Median 69/70	7M, 11F	Descriptive (narrative analysis)	To investigate how the experience of breathlessness in COPD influences patients' attitudes toward the end of life and their quality of life

Habraken #49	2008	Netherlands	Interviews	COPD	Outpatient clinics and respiratory centre	Purposive	11 patients	61-83	8M, 3F	Descriptive (thematic analysis)	To gain insight into why patients with end-stage COPD tend not to express a wish for help
Halding #50	2012	Norway	Serial interviews	COPD	Pulmonary rehabilitation (outpatient)	Purposive (maximum variation)	18 patients	52-81	13M, 5F	Descriptive (thematic analysis)	To explore the experience of patients with COPD in terms of their transitions in health during and after pulmonary rehabilitation
Hall #53	2010	Canada	Interviews	COPD	Acute hospital	Patients screened against eligibility criteria.	6 patients	Mean age 69	4M, 2F	Descriptive (exploratory descriptive)	To describe the perceptions of people living with severe COPD with respect to the end of life
Harris #55	2008	UK	Interviews	COPD	Community	Purposive	16 patients	Mean age 66.8	12M, 4F	Theory building (grounded theory)	To assess patients' concerns about accepting an offer of pulmonary rehabilitation
Hasson #58	2009	Canada	Interviews	COPD	Community	Care-givers screened against eligibility criteria. Those eligible who agreed to participate included.	9 care-givers	25-65	2M, 7F	Descriptive (content analysis)	To explore the experiences of palliative care that bereaved carers had while providing care to a dying loved one with COPD
Hasson #57	2008	UK	Interviews	COPD	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	13 patients	45-65	10M, 3F	Descriptive (content analysis)	To explore the potential for palliative care among people living with COPD

Hayle #59	2013	UK	Interviews	COPD	Specialist palliative care	Participants recruited against eligibility criteria. Those eligible who agreed to participate included.	8 patients	63-77	5M, 3F	Theory informed (phenomenological-hermeneutic approach)	To evaluate the experiences of patients with COPD who accessed palliative care
Hellem #61	2012	Norway	Interviews and focus groups	COPD	Pulmonary rehabilitation (outpatient)	Purposive	11 patients	53-68	3M, 8F	Theory informed (phenomenological approach)	To elucidate how patients with COPD who successfully maintain a long term exercise programme understand concordance with maintenance exercise and see potential solutions
Hogg, L. #62	2012	UK	Focus groups	COPD	Pulmonary rehabilitation (outpatient)	Purposive	16 patients	Patients divided into two groups. Group 1 = 71 (mean). Group 2 = 67 (mean)	9M, 7F	Theory building (grounded theory)	To understand the views and perceptions of patients with COPD regarding maintaining an active lifestyle following a course of pulmonary rehabilitation
Hopley, #63	2009	New Zealand	Interviews	COPD	Community	Purposive	9 patients	50-80	Not stated	Descriptive (general inductive approach)	To understand the challenges people living with COPD in rural areas face in accessing specialist health care services
Hynes, G #65	2012	Ireland	Interviews	COPD	Community	Patients identified care-givers. All invited to participate. Owing to small numbers, further recruitment in patient support groups and advertisements in media.	11 care-givers	20-79	2M, 9F	Descriptive (thematic analysis)	To explore the experiences of informal caregivers providing care in the home to a family member with COPD

Jackson, #66	2012	Canada	Case study	COPD	Community	Convenience	4 patients	57-81	3F, 1M	Descriptive (thematic analysis)	To understand older patients with COPD experiences of their journeys through the health system
Jonsdottir #71	2007	Iceland	Serial interviews	COPD	Community	Convenience	7 patients	40-65	7F	Theory informed (interpretive phenomenology)	To explore the experience of women with advanced COPD of repeatedly relapsing to smoking
Kanervisto #72	2007	Finland	Interviews	COPD	Hospital	Participants selected by clinicians	5 patients, 4 spouses	Not stated	Patients = 3M, 2F. Spouses = 3F, 1M	Descriptive (deductive content analysis)	To describe the coping of the families of people with advanced COPD
Kauffman, #73	2014	USA	Focus groups	COPD	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	18 patients	49-75	12M, 6F	Descriptive (thematic analysis)	To describe the subjective sleep complaints of patients with COPD along with their attributions as to the cause of these symptoms and their treatment preferences for insomnia
Keating #74	2011	Australia	Interviews	COPD	Pulmonary rehabilitation (outpatient)	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	37 patients	53-86	18M, 19F	Descriptive (thematic analysis)	To understand what prevents people with COPD from attending and completing pulmonary rehabilitation
Kerr #75	2010	UK	Interviews	COPD	Pulmonary rehabilitation (outpatient)	All patients attending pulmonary rehabilitation invited to participate. Those who agreed to participate accepted on study.	9 patients	62-80	6M, 3F	Theory building (grounded theory)	To understand from an occupational perspective how patients live with COPD

Kvangarsnes #77	2013	Norway	Interviews	COPD	Acute hospital	Purposive	10 patients	45-85	5M, 5F	Descriptive (narrative analysis)	To explore patient perceptions of COPD exacerbation and experiences of their relations with health personnel during care and treatment
Lewis #79	2014	UK	Interviews	COPD	Pulmonary rehabilitation (community)	Convenience	25 patients	42-90	Not stated	Theory informed (interpretative phenomenological approach)	To explore the lived experience of COPD patients referred to pulmonary rehabilitation programmes prior to participation
Lewis #80	2010	UK	Focus group	COPD	Community	Purposive	6 patients	61-83	1M, 5F	Descriptive (thematic analysis)	To explore the attitudes of people with COPD to exercise and reasons for non-concordance with exercise maintenance post pulmonary rehabilitation
Lindgren #81	2014	Norway	Interviews	COPD	Community	Purposive	8 patients	60-74	3M, 5F	Theory informed (phenomenological-hermeneutic approach)	To illuminate patients' lived experiences of being diagnosed with COPD
Lindqvist #82	2013	Sweden	Serial interviews	COPD	Community	Purposive	21 spouses	53-84	21F	Theory informed (phenomenography)	To describe the conceptions of daily life in women living with a man suffering from COPD in different stages

Lindqvist #83	2010	Sweden	Serial interviews	COPD	Acute hospital	Open sampling initially then theoretical sampling in order to saturate emerging categories	23 patients	52-82	10M, 13F	Theory building (grounded theory)	To illuminate the main concern of patients with COPD and how they handle their everyday life
Lindqvist #159	2013	Sweden	Serial interviews	COPD	Community	Purposive	19 spouses	55-85	19M	Theory informed (phenomenography)	To describe the conceptions of daily life in men living with a woman suffering from COPD in different stages
Lomborg, K.#86	2008	Denmark	Participant observation and interviews	COPD	Acute hospital	Patients screened against eligibility criteria and consecutively included. Further sampling selective and theoretical.	12 patients, 4 HCPs	Patients = >30. HCPs not stated	Not stated	Theory building (grounded theory)	To explore COPD patients' and nurses' expectations, goals and approaches to assisted personal body care.
Lundh, L. #87	2012	Sweden	Interviews	COPD	Community	Participants screened against eligibility criteria and recruited consecutively.	14 patients	47-83	7M, 7F	Theory building (grounded theory)	To investigate why some patients with COPD have difficulty quitting smoking and to develop a theoretical model that describes their perspectives on these difficulties.
Luz, E. L #88	2013	Portugal	Interviews	COPD	Community	Convenience and theoretical sampling	22 patients	26-72	17M, 5F	Theory building (grounded theory)	To understand how people live with COPD

MacPherson, A. #89	2013	UK	Interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	10 patients	58-86	9M, 1F	Theory building (grounded theory)	To explore the views of people with severe COPD about advance care planning
Mathar, H. #90	2015	Denmark	Interviews	COPD	Community	Purposive	6 patients	67-83	3M, 3F	Descriptive (text condensation method)	To understand the experiences and preferences of COPD patients in relation to discharge from hospital with televideo consultations
McMillan Boyles, C #93	2011	Canada	Interviews	COPD	Community	Purposive	15 patients	>50	Not stated	Descriptive (narrative analysis)	To develop an understanding of the meaning of disability for individuals living with COPD
Meis, J #94	2014	Netherlands	Interviews and focus groups	COPD	Pulmonary rehabilitation (inpatient)	Patients screened against eligibility criteria. Those eligible who agreed to participate included. HCPs randomly invited to participate.	13 patients, 14 HCPs	Patients = 54 -78. HCPs = 24-52	Patients = 8M, 5F. HCPs = 3M, 11F	Theory informed (descriptive phenomenological approach)	To assess COPD patients' experiences during an inpatient pulmonary rehabilitation program
Moore, #96	2012	UK	Interviews	COPD	Pulmonary rehabilitation (community)	Random sampling of three groups meeting different eligibility criteria. Patients recruited until data saturation had been achieved.	24 patients	47-84	14M, 10F	Descriptive (framework approach)	To assess the obstacles to participation in pulmonary rehabilitation among COPD patients in a community based pulmonary rehabilitation programme and associated general practices

Mousing #97	2012	Denmark	Interviews and focus groups	COPD	Community	Interviews: participants screened against eligibility criteria and then consecutively recruited until recruitment target met. Focus group: all participants attending patient education sessions invited to participate.	11 patients	51-75	3M, 8F	Descriptive (thematic analysis)	To explore how group patient education influences the self-care of patients with COPD
Nykvist #100	2014	Sweden	Interviews	COPD	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	6 patients	Not stated	6F	Descriptive (narrative analysis)	To describe how a group of smoking women with COPD experienced their everyday life and their relationship to smoking
Panos #107	2013	USA	Focus groups	COPD	Community	Participants were selected by systematic sampling against eligibility criteria and consecutively recruited until recruitment target met.	42 patients	48-88	42M	Descriptive (thematic analysis)	To determine the perceptions of veterans with COPD about their disease, its effects on their lives and their interactions with the Veterans' Healthcare Administration
Philip #108	2012	Australia	Interviews and focus groups	COPD	Acute hospital	Patients screened against eligibility criteria. Patients recruited consecutively until data saturation had been achieved. HCPs sampled purposively.	10 patients, 31 HCPs	Patients = 55-76. HCPs = 23-61	Patients = 6M, 4F. HCPs not stated	Descriptive (thematic analysis)	To explore the views of patients with COPD and HCPs focusing upon information needs and treatment preferences

Philip #109	2014	Australia	Interviews	COPD	Community	Care-givers identified by patient or physician. Those who agreed to participate included in study.	19 care-givers	28-83	9M, 10F	Descriptive (thematic analysis)	To understand the experiences and needs of family carers of people with severe COPD
Pinnock #110	2011	UK	Serial interviews and focus groups	COPD	Community	Purposive	21 patients, 13 care-givers, 18 HCPs	Patients = 50-83. Care-givers and HCPs not stated.	Patients = 14M, 7F. Care-givers and HCPs not stated.	Descriptive (thematic narrative analysis)	To understand the perspectives of patients with severe COPD as their illness progresses, and of their informal and professional carers
Reinke #112	2008	USA	Serial interviews	COPD or cancer	Community	HCPs: Drs screened against eligibility criteria, classified into specialty categories and then randomly selected. Nurses identified by patients or drs. Patients: identified by HCPs against eligibility criteria. Relatives: identified by patients.	55 patients, 56 HCPs, 36 relatives	Patients = 67.3 (mean), relatives = 60.3 (mean), HCPs = 47 (mean)	Patients = 22M, 33F. Relative s = 18M, 18F. HCPs = 22M, 34F	Theory building (grounded theory)	To examine participants' perspectives on the experiences of key transitions in the context of living with advanced COPD or cancer
Schroedl #117	2014	USA	Interviews	COPD	Acute hospital	Purposive	20 patients	52-83	9M, 11F	Descriptive (thematic analysis)	To understand the unmet health care needs among patients to help determine which aspects of palliative care are most beneficial

Seamark #119	2012	UK	Interviews	COPD	Community	Patients screened against eligibility criteria. All eligible patient invited to participate.	16 patients	58-83	12M, 4F	Descriptive (content analysis and constant comparison)	To examine whether an admission to hospital for an exacerbation of COPD is an opportunity for advance care planning (ACP) and to understand, from a pt perspective, the optimum circumstance for ACP
Sheridan #121	2011	New Zealand	Interviews	COPD	Community	Pragmatic (8 patients initially interviewed, further participants from a certain ethnic group recruited in order to explore theme further)	29 patients	50-89	15M, 14F	Descriptive (thematic analysis)	To explore how patients with COPD experience helplessness
Shipman #122	2009	UK	Interviews	COPD	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included. 4 patients excluded post interview as did not meet eligibility criteria.	16 patients	54-86	9M, 7F	Descriptive (framework approach)	To explore factors that influence the use of general practice services by people with advanced COPD
Shum #123	2014	Canada	Interviews and focus groups	COPD	Community	Convenience	30 patients, 16 care- givers	Not stated	Not stated	Descriptive (thematic analysis)	To investigate how patients with COPD from new immigrant communities received and utilised information about their condition and its management

Simpson #125	2010	Canada	Interviews	COPD	Community	Purposive	14 care-givers	46-89	3M, 11F	Descriptive (interpretive description)	To understand the extent and nature of 'burden' experienced by informal care-givers in advanced COPD
Simpson #156	2012	Canada	Serial dialogue	COPD	Community	Participants screened against eligibility criteria.	8 patients , 8 care-givers	Patients = 53-76. Care-givers not stated.	Patients = 4M, 4F. Care-givers = 3M, 5F	Descriptive (interpretive description)	To understand what is required for meaningful and effective advance care planning in the context of advanced COPD
Small #191	2012	UK	Interviews and focus groups	COPD	Community	Patients screened against eligibility criteria then randomly selected and invited to participate. Those eligible who agreed to participate included. Staff recruited from primary and secondary care with range of staff characteristically involved in COPD care (drs and nurses)	21 patients , 39 HCPs	Patients = 57-78. HCPs = 25-63	Split site study. Only one set of patients/H CPs reported on. Patients = 7M, 6F. HCPs = 6M = 6; F = 14	Descriptive (thematic analysis)	To report patients, family members and HCPs' experiences of COPD
Sorensen #128	2013	Denmark	Participant observation , interviews	COPD	Acute hospital	Participants screened against eligibility criteria. Those eligible who agreed to participate included. Recruitment continued until conceptual density achieved.	21 patients (obs) 11 patients (ints)	43-81	11M, 10 F	Theory building (grounded theory)	To present a theoretical account of the pattern of behaviour in patients with acute respiratory failure owing to COPD while undergoing non-invasive ventilation

Sossai #129	2011	Australia	Interviews	COPD	Community	Purposive	8 patients	50-85	5M, 3F	Descriptive (thematic analysis)	To explore the experience of living with COPD
Spence #130	2008	UK	Interviews	COPD	Community	Purposive	7 care-givers	55-65	1M, 6F	Descriptive (content analysis similar to constant comparison)	To explore the specific care needs of informal care-givers of patients with advanced COPD
Strang #133	2013	Sweden	Interviews	COPD	Community	Purposive (maximum variation)	31 patients	48-85	15M, 16F	Descriptive (thematic content analysis)	To explore perceptions of anxiety and the alleviation strategies that are adopted by patients with COPD
Thorpe #137	2014	Australia	Interviews	COPD	Hospital	Purposive	28 patients	Mean age 71.86	22M, 6F	Descriptive (content analysis)	To explore the barriers to and enablers of participation in physical activity following hospitalisation for COPD
Torheim #138	2010	Norway	Interviews and focus groups	COPD	Acute hospital	Purposive	5 patients , 8 nurses	Patient s = 45-78. Nurses not stated.	Patients = 2M, 3F. Nurses not stated.	Theory informed (phenomenological approach)	To explore the experiences of mask treatment in patients with acute exacerbations of COPD
Torheim #139	2014	Norway	Interviews	COPD	Acute hospital	Strategic (recruited to meet eligibility criteria)	10 patients	45-85	5M, 5F	Theory informed (phenomenological approach: meaning condensation)	To gain insight how patients with advanced COPD experience care in the acute phase (specifically in the intensive care unit)

Willgoss #145	2012	UK	Interviews	COPD	Community	Purposive (nonprobabilistic)	14 patients	Mean age 62.3	5M, 9F	Descriptive (thematic network analysis)	To elicit and describe the first-hand experiences of anxiety in community patients with stable COPD
Williams #147	2010	UK	Interviews	COPD	Pulmonary rehabilitation (outpatient)	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	9 patients	54-84	6M, 3F	Theory building (grounded theory)	To explore how pulmonary rehabilitation affects the experience of activity and breathlessness of people with COPD
Williams #146	2007	UK	Interviews	COPD	Community	Purposive	6 patients	64-83	4M, 2F	Descriptive (thematic analysis)	To investigate what is most important to people living with COPD
Williams #148	2011	UK	Interviews	COPD	Community	Purposive and theoretical sampling	18 patients	54-84	12M, 6F	Theory building (grounded theory)	To understand how people with COPD experience activity
Wilson #150	2008	Canada	Serial interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	12 patients	Not stated	Not stated	Descriptive (constant comparison approach)	To determine the care needs of seniors living at home with advanced COPD
Wilson #152	2007	UK	Focus groups	COPD	Community	Purposive	32 patients, 8 HCPs	Patients = 56-82. HCPs not stated.	Patients = 25M, 7F. HCPs not stated	Theory building (grounded theory)	To ascertain what should be included in the educational component of pulmonary rehabilitation
Wodsku #153	2014	Denmark	Interviews and focus groups	COPD	Community	Purposive	34 patients, 8 relatives	Patients = 48-87; Relatives = not stated	Patients = 15M, 9F. Relatives = 3M, 5F	Descriptive (content analysis)	To examine the experiences of COPD patients and their relatives of integrated care

LUNG CANCER

Author	Year	Country	Qual method	Index condition	Setting	How sampled?	Sample	Age of sample	Gender of sample	How data analysed?	Study details
Amichai #3	2012	Canada	Interviews	Lung cancer	Acute hospital	Purposive	12 patients	40-70	6M, 6F	Descriptive (interpretative)	To understand lung cancer patients' beliefs about complementary and alternative medicine use in promoting their own wellness
Arber #226	2013	UK	Interviews	Lung cancer	Acute hospitals	Theoretical sampling until data saturation achieved	10 patients	56-82	8M, 2F	Theory building (grounded theory)	To explore patients' experience during the first 3 months following a diagnosis of malignant pleural mesothelioma
Baker #8	2012	UK	Interviews	Breast, lung or prostate cancer	Acute hospitals	Purposive. Recruitment continued until theoretical saturation reached.	42 patients	36-86	23M, 19F	Descriptive (constant comparison technique)	To investigate the readiness of patients to address emotional needs up to 18 months following a diagnosis of cancer
Bertero #11	2008	Sweden	Interviews	Lung cancer	Acute hospitals	Purposive	23 patients	36-86	12M, 11F	Theory informed (phenomenological-hermeneutic approach)	To describe how having inoperable lung cancer affects the patients' life situation and quality of life
Brown #300	2015	Australia	Interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	10 patients	50-89	8M, 2F	Theory building (grounded theory)	To explore the supportive care needs and preferences of lung cancer patients
Carrion #16	2013	USA	Interviews	Lung, brain, colorectal, prostate cancer	Community	Purposive	15 patients (2 living with lung, 2 brain, 2 colorectal, 9 prostate)	31-71	15M	Descriptive (thematic analysis)	To explore beliefs and treatment decisions of Latino men with cancer

Caughlin #160	2011	USA	Interviews	Lung cancer	Community	Participants recruited by advertisement and screened against eligibility criteria. Those who agreed to participate, included.	35 family members	36-72	6M, 29F	Theory building (grounded theory)	To examine families' communication and coping in response to a parent's lung cancer
Dale #161	2011	UK	Interviews	Lung cancer	Palliative care	Purposive	6 patients	67-81	2M, 4F	Descriptive (thematic analysis)	To explore the concerns of patients with inoperable lung cancer
Dorman #112	2009	UK	Interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included. Recruitment continued until no new themes emerged.	9 patients	Not stated	5M, 4F	Theory informed (Interpretative Phenomenological Analysis)	To study what patients with recently diagnosed brain metastases from NSCLC want from their treatment
Epiphaniou #270	2014	UK	Serial interviews	Lung cancer and COPD	Acute hospital	Purposive	18 patients (11 living with lung cancer, 7 COPD)	52-90	12M, 6F	Descriptive (thematic analysis)	To explore patients' experience of care coordination in COPD and lung cancer
Eustache #271	2014	Canada	Interviews	Lung cancer	Cancer centre	Purposive (maximum variation)	12 patients	36-78	6M, 6F	Descriptive (interpretative)	To explore the experience and meaning of hope in relation to the healing process of patients living with lung cancer
Farley #349	2015	UK	Interviews	Lung cancer	Acute hospital	Purposive	22 patients	39-82	12M, 10F	Descriptive (framework approach)	To explore lung cancer patients' views about smoking and about their preferences for support to help them quit

Gerber #195	2012	USA	Focus groups	Lung cancer	Cancer centre/acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	13 patients	39-69	7M, 6F	Descriptive (thematic content analysis)	To gain insight into patients' perceptions of maintenance chemotherapy
Hamilton #135	2010	USA	Focus groups	Lung, colon, breast, other cancer	Outpatient oncology clinics	Purposive. Recruitment continued until theoretical saturation reached.	22 patients (4 living with lung, 9 breast, 2 colon, 7 other)	50-80	7M, 15F	Theory building (grounded theory)	To explore the perceived social support needs among older African American cancer survivors
Hendriksen #312	2015	USA	Interviews	Lung cancer	Cancer centres	Patients screened against eligibility criteria. Caregivers nominated by patient and screened against eligibility criteria.	11 patients, 10 caregivers	Patients = 36-78. Caregivers = 34-74	Patients = 8F, 3M. Caregivers = 5F, 5M	Theory building (grounded theory)	To explore the nature of shared anxiety and its impact on patient-caregiver dyads
Hoff #64	2014	Sweden	Serial interviews	Malign haematological disease or lung cancer	Acute hospitals	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	12 patients (5 living with lung, 7 haematological)	37-80	5M, 7F	Descriptive (content analysis)	To identify challenges in communicating with patients with lung cancer about their imminent death
Hoffman #276	2014	USA	Focus groups	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	6 patients	53-73	2M, 4F	Descriptive (directed content analysis)	To identify the postsurgical NSCLC patients' unmet supportive care needs during transition from hospital to home

Horne #50	2006	UK	Interviews	Lung cancer	Community	Purposive	9 patients	52-87	3M, 6F	Theory building (grounded theory)	To develop and pilot an advance care planning intervention for lung cancer nurses
Horne #200	2012	UK	Interviews	Lung cancer	Cancer centres	Purposive	25 patients, 19 family members	47-85 (patients). Family members not stated	18M, 7F. Family members not stated.	Theory building (grounded theory)	To explore the views and experiences of people affected by lung cancer about discussing preferences and wishes for end of life care and treatment
John #141	2010	USA	Interviews	Lung cancer	Cancer centres	Purposive	10 patients	48-87	6M, 4F	Descriptive (content analysis)	To describe self care strategies used by patients with lung cancer to promote quality of life
Krishnasamy #68	2007	UK	Serial interviews	Lung cancer	Cancer centres	Participants screened against eligibility criteria. Those eligible, who wished to participate, included. Recruitment continued until data saturation achieved.	60 patients, 31 family members	Patients = 38-82. Family members not stated.	Patients = 32M, 28F. Family members = 4M, 27F	Theory building (grounded theory)	To explore the experiences of care provision of patients with lung cancer and their carers
Lee #120	2009	Australia	Case study report	Lung cancer	Community	Convenience	2 patients, 6 care-givers, 5 HCPs	Not stated	Not stated	Descriptive (constant comparison technique)	To identify common issues and to explore the needs and experiences of people with lung cancer, their carers and service providers
Lehto #283	2014	USA	Focus groups	Lung cancer	Community hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	11 patients	51-79	5M, 6F	Descriptive (thematic analysis)	To describe the lung cancer experience in relation to perceived stigmatization, smoking behaviours and illness causes

Lowe #570	2011	UK	Serial interviews	Lung cancer	Cancer centre	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	17 patients, 15 care- givers	Patient s = 48- 93. Care- givers = 40-81	Patient s = 12M, 5F. Care- givers = 5M, 10F	Theory informed (Interpretative Phenomenologic al Analysis)	To explore factors that influence patient distress within the lung cancer population
Lowson #571	2013	UK	Interviews	Heart failure, lung cancer	Acute hospital and communi- ty	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	27 patients (14 living with lung, 13 heart failure)	69-89	13M, 14F	Descriptive (framework approach, thematic analysis)	To explore the meanings of family caring for care recipients
Maguire #576	2014	UK	Interviews	Lung cancer	Acute hospital	Purposive	10 patients	47-80	4M, 6F	Theory informed (Interpretative Phenomenologic al Analysis)	To explore the lived experience of multiple concurrent symptoms in people with lung cancer
McCarthy #587	2009	Ireland	Interviews	Lung cancer	Acute hospital	Purposive	6 patients	53-74	2M, 4W	Theory informed (Interpretative Phenomenologic al Analysis)	To explore patients' experiences of living with NSCLC
Missel #597	2015	Denmark	Interviews	Lung cancer	Acute hospital	Criteria sampling approach (to select cases of predetermined criteria of importance)	19 patients	42-79	7M, 12F	Theory informed (Ricoeur's theory of interpretation)	To investigate how the diagnosis affects the daily lives of patients with operable lung cancer
Molassiotis #598	2011	UK	Serial interviews	Lung cancer	Cancer centre	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	17 patients, 15 care- givers	Patient s = 48- 93. Care- givers = 40-81	Patient s = 12M, 5F. Care- givers = 5M, 10F	Theory informed (Interpretative Phenomenologic al Analysis)	To explore lung cancer patients experiences of symptom clusters

Mosher #604	2015	USA	Interviews	Lung cancer	Cancer centre	Purposive	21 patients, 21 care-givers	Patients = 39-80. Care-givers = 38-78	Patients = 10M, 11F. Care-givers = 6M, 15F	Descriptive (thematic analysis)	To identify strategies for coping with various physical and psychological symptoms among advanced symptomatic lung cancer patients and their primary family care-givers
Petri #758	2015	Denmark	Interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	3 patients	65-72	2M, 1F	Theory informed (descriptive phenomenology)	To explore and describe the essential meaning of lived experiences of everyday life during curative radiotherapy in patients with NSCLC
Pollock #760	2008	UK	Serial interviews	Lung cancer and head & neck	Acute hospital	Patients screened against eligibility criteria. Those eligible, who wished to participate, included. Family members nominated by patients.	27 patients (15 living with lung, 12 H&N). 20 family members	Patients = 41 - 85. Family members not stated	Patients = 23M, 8F	Descriptive (thematic analysis)	To investigate service users' experiences of information delivery after a diagnosis of cancer
Powell #763	2015	UK	Interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	15 patients	58-87	5F, 10M	Descriptive (framework approach)	To explore patients' attitudes to the risks associated with lung cancer surgery
Robinson #777	2011	Canada	Interviews	Lung cancer	Community	Participants screened against eligibility criteria. Family members nominated by patients.	9 patients, 9 family members	Not stated	Not stated	Descriptive (constant comparison technique)	To explore the applicability and usefulness of an advanced care planning (ACP) intervention and examine the ACP process

Salander #786	2014	Sweden	Serial interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria and consecutively included.	15 patients	56-85	4M, 11F	Descriptive (constant comparison technique)	To understand how patients with lung cancer reflect upon their life situation after diagnosis and treatment
Sandema n #789	2011	UK	Interviews	Lung cancer	Acute hospital	Purposive	10 patients	46-82	4M, 6W	Descriptive (framework approach)	To explore the experiences of lung cancer patients attending routine follow up
Sjolander #931	2008	Sweden	Interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	10 patients	47-88	8M, 2F	Descriptive (constant comparison technique)	To identify and describe the impact that social support and a social network has for patients with lung cancer
Steinvall #938	2011	Sweden	Interviews	Lung cancer	Acute hospital	Purposive	11 family members	56-73	7M, 4F	Theory informed (phenomenologi cal-hermeneutic approach)	To identify and describe the experiences of quality of life/life situation among those who were next of kin to persons with inoperable lung cancer
Stone #941	2012	USA	Interviews	Lung cancer	Communi ty	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	35 family members	36-72	6M, 29F	Descriptive (constant comparison technique)	To investigate communication and care in the context of lung cancer
Thornton #948	2011	UK	Interviews	Lung cancer	Cancer centre	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	5 patients	39-67	4M, 1F	Descriptive (thematic content analysis)	To explore the factors that influence patients' choice of treatment during the oncologist- patient consultation

Treloar #957	2009	Australia	Focus groups	Lung cancer	Acute hospitals	Participants screened against eligibility criteria. Recruitment continued until no new themes emerged.	22 patients, 13 care-givers	Patient s = 37-83. Care-givers = 39-75	Patient s 17M, 5 F. Care-givers = 1M, 12F	Descriptive (thematic analysis)	To identify the needs of people with NSCLC and their carers in relation to quality of life issues
Wickersham #975	2014	USA	Interviews	Lung cancer	Cancer centre	Purposive	13 patients	52-83	5M, 8F	Theory building (grounded theory)	To explore the process of medication-taking for NSCLC patients receiving oral epidermal growth factor receptor inhibitors

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Patients and informal caregivers' experiences of burden of treatment in lung cancer and chronic obstructive pulmonary disease (COPD): a systematic review and synthesis of qualitative research

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Patients and informal caregivers’ experiences of burden of treatment in lung cancer and chronic obstructive pulmonary disease (COPD): a systematic review and synthesis of qualitative research

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MeSH terms: Lung Neoplasms; Pulmonary Disease, chronic obstructive; Qualitative research

ABSTRACT.

Objective:

To identify, characterise and explain common and specific features of the experience of treatment burden in relation to patients living with lung cancer or chronic obstructive pulmonary disease (COPD) and their informal caregivers.

Design:

Systematic review and interpretative synthesis of primary qualitative studies. Papers were analysed using constant comparison and directed qualitative content analysis.

Data sources:

CINAHL, EMBASE, MEDLINE, PsychINFO, Scopus and Web of Science searched from January 2006 to December 2015.

Eligibility criteria for selecting studies:

Primary qualitative studies in English where participants were patients with lung cancer or COPD and/or their informal caregivers, aged >18 that contain descriptions of experiences of interacting with health or social care in Europe, North America and Australia.

Results:

We identified 127 articles with 1,769 patients and 491 informal caregivers. Patients, informal caregivers and healthcare professionals (HCPs) acknowledged lung cancer's existential threat. Managing treatment workload was a priority in this condition, characterised by a short illness trajectory. Treatment workload was generally well supported by an immediacy of access to healthcare systems and a clear treatment pathway. Conversely, patients, informal caregivers and HCPs typically did not recognise or understand COPD. Treatment workload was balanced with the demands of everyday life throughout a characteristically long illness trajectory. Consequently, treatment workload was complicated by difficulties of access to, and navigation of, healthcare systems, and a fragmented treatment pathway. In both conditions, patients' capacity to manage workload was enhanced by the support of family and friends, peers and HCPs and diminished by illness/smoking related stigma and social isolation.

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Conclusion:

This interpretative synthesis has affirmed significant differences in treatment workload between lung cancer and COPD. It has demonstrated the importance of the capacity patients have to manage their workload in both conditions. This suggests a workload which exceeds capacity may be a primary driver of treatment burden.

Systematic review registration number:

PROSPERO CRD42016048191

Strengths and limitations of this study:

- To the best of our knowledge, this is the first systematic review and synthesis that compares treatment burden in malignant and non-malignant disease
- The review synthesises patient and informal caregiver experience of treatment burden across a wide range of healthcare settings and systems
- The heterogeneity of studies included means uniformities highlighted should facilitate the development of an explanatory model of burden of treatment
- The data analysed, whilst ostensibly from primary sources, are seen through the multiplicity of theoretical lenses chosen by the studies’ authors and their varying epistemological and ontological stances and, indeed, the authors’ own which may be a limitation of the study

Introduction:

Burden of treatment (BoT) is not simply the unavoidable workload that illness inevitably confers on patients and their informal caregivers but is a potentially *modifiable* workload which treatment for the illness may create (1). This workload consists of affective, cognitive, informational, material, physical and relational tasks delegated to patients and/or their informal caregivers by HCPs (1, 2). The literature on BoT discusses the concept of “capacity” and defines this as the resources (which may be affective, cognitive, informational, material, physical and relational) and limitations that affect patients’ capability to carry out the work of chronic illness (1, 3, 4). Capacity may be viewed at an individual (i.e. the patient) or collective level (i.e. the patients’ social network) (5). Capacity may be affected by a range of variables, from socio-economic factors such as ethnicity and poverty, to the social skill necessary to engage and mobilize stakeholders (1-4, 6-12). A workload that exceeds capacity might, in some cases, be a primary driver of BoT for patients (1, 4). Neither workload nor capacity are static. They may fluctuate over time as illness progresses, functional capacity declines and patients’ social networks change (1, 3, 4) or, indeed, as the patient is able to accept, adapt and normalise their condition into their daily life (2, 9, 12, 13).

The literature (1, 7, 11, 14, 15) emphasises the importance of adequately equipping clinicians with tools to detect BoT and training in interventions that might ameliorate burden in order to provide “minimally disruptive medicine” (15). This is an approach to healthcare that takes into account patient priorities, multi-morbidity and seeks to reduce the BoT on the patient and informal caregiver (15).

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COPD and lung cancer are the most common causes of respiratory-related mortality in the United Kingdom (UK), excluding pneumonia (16). Tobacco smoking is the main risk factor for both diseases, linked to an estimated 86% of lung cancer and 90% of COPD cases in the UK (17, 18). Thus, both may carry the stigma of a ‘self-inflicted’ disease (19, 20).

Tobacco is a legal drug, used commonly, and has been previously socially acceptable. More recently, recognition of the significant risks of tobacco smoking and public health strategies to ‘de-normalise’ tobacco have contributed to a social transformation that actively stigmatizes smokers (21).

COPD generally has a protracted trajectory of increasing respiratory limitation, punctuated by recurrent episodes of worsening termed “exacerbations”. Globally, COPD is a major cause of chronic morbidity and mortality; prognosis is uncertain but many people die prematurely because of the disease or its complications (such as pneumonia) (22). Conversely, lung cancer typically has a rapid trajectory involving steady progression with a clear terminal phase (23). The prognosis for lung cancer is poor; only 1 in 10 patients in the UK live for more than 5 years after diagnosis. Lung cancer treatments in England are predominantly hospital-based: outpatient chemotherapy or systemic anti-cancer treatment or inpatient surgical treatment (24). In contrast, treatment for COPD generally involves self-management (management of treatment regimens by patients and informal caregivers in the home) (25). BoT may, therefore, be experienced very differently by patients living with these two common respiratory conditions.

Aim of the review:

We aimed to undertake a comprehensive search of the literature to identify, characterise and explain common and specific features in the experiences of treatment burden in relation to patients living with either lung cancer or COPD.

Research question:

What is burden of treatment in lung cancer and COPD and how is it experienced by patients and their informal caregivers?

Methods:

Identifying relevant studies:

This review forms part of a larger body of work which we are undertaking in order to identify, characterise and explain the intricate interpersonal and institutional processes that mediate patient and informal caregiver experiences of their interactions with healthcare. Thus, for this study we replicated and extended a previously developed search strategy which was built around three search concepts (26):

- (i) index conditions (heart failure, chronic kidney disease and COPD)
- (ii) qualitative research methodology terms
- (iii) patient/informal caregiver experience.

We initially ran the search based on the above index conditions. We subsequently ran a separate search with lung cancer as the index condition. The full search strategy as performed in MEDLINE is available in Appendix 1. The search was piloted in MEDLINE and then adapted for other electronic databases used (CINAHL, Embase, Scopus, Web of Science, PsycInfo). We looked at primary qualitative studies

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examining patients with COPD or lung cancer and their informal caregivers' interactions with health and social care, rather than studies which explicitly examine treatment burden in COPD or lung cancer as there are so few. Searches were limited to countries with advanced healthcare systems comparable to the UK as the synthesis is intended to inform a future research project that will take place in the National Health Service (NHS) in England. We limited our search to publications from the year 2006 onwards. This is because, like Gallacher et al (7), we wanted to locate patient/informal caregiver experiences of BoT in current rather than historical health and social care practices. After retrieving and screening full text articles, we decided not to use the mixed methods studies identified, as the majority of these studies screened suggested the qualitative components of the studies addressed a very specific research question, meaning that there was little data relevant to our research question. This is a potential limitation of the systematic review as there is a possibility that we have missed some pertinent studies. Table 1 details inclusion/exclusion criteria.

Study selection:

KAL, MM, AC and CRM individually screened batches of citations and abstracts to assess eligibility against the inclusion/exclusion criteria. A further reviewer (JH, see acknowledgements) resolved eligibility disagreements at this stage. We obtained studies in full text where it was not immediately possible to determine eligibility against inclusion/exclusion criteria. KAL, MM AND JH independently double screened all full-text COPD articles for eligibility; KAL screened all full-text lung cancer articles for eligibility with 10% of the full text papers screened by CRM. A further reviewer (KH, see acknowledgements) resolved eligibility disputes at this stage.

Quality assessment:

MM, AC, JH and KAL undertook quality assessment of included papers using a modified version of the qualitative appraisal tool: RATS (relevance, appropriateness, transparency, soundness) guidelines (27) (see Appendix 2). We took a conservative approach to assessment, primarily undertaking it to ensure transparency of study design, aims and the sampled population. Thus, we excluded only five of the lung cancer studies that had not appeared to seek ethical permissions.

Data extraction and analysis:

We extracted data from the findings/results, discussion and conclusion sections of each paper. Extracted data included verbatim quotes from patients and caregivers and authors' interpretations (2). As the aim of the review was to identify and characterise patient and informal caregiver experience, we omitted results relating to HCPs in the analysis (n=12 of studies included HCPs). CRM, AR, KAL, MM, AC and JH developed a coding framework, underpinned by robust, empirically derived, middle-range theories: BoT theory (described above) (1) and status passage theory (28). Middle range theories are applicable to discrete conceptual ranges, sitting between frequently generated minor working hypotheses and all-encompassing efforts to explain systematically the observed uniformities of society. They may be particularly helpful, therefore, in generalising learning in health services improvement so that interventions can be replicated in different contexts (29). Status passage theory describes people as constantly in passage between temporally limited and societally ascribed statuses (for example, from being unmarried to married). Status passages may (or may not) be desirable, inevitable, reversible, repeatable or voluntarily undertaken. They may vary in their importance to the person undergoing the passage. Passages may have to be legitimized by authorized agents. Status passage theory is a particularly useful tool

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when considering illness, which is an undesirable, involuntary and often irreversible passage, legitimized by HCPs as authorized agents (28).

In keeping with the principles of directed qualitative content analysis which seeks to extend conceptually an existing theory, we identified key concepts of BoT and status passage theories as coding categories and determined operational definitions for these creating a coding framework (30). KAL, MM, AC and JH then independently used the coding framework to code a selected group of data and compared results. Once inter-coder reliability had been established, KAL downloaded full-text articles into the qualitative data analysis software Nvivo 11, used to organise and manage data. KAL read the full text versions of identified papers to enable immersion in the data to understand their scope and context (31). and coded data using the coding framework described above. KAL, supported by CRM and AR analysed data using directed qualitative content analysis (30) and constant comparison (32). We grouped related codes into sets for each condition and compared sets within and between conditions. We used Shippee et al's (4) proposition that a workload that exceeds capacity might be the primary driver of BoT.and thus grouped coded data into sets of **workload** (the affective, cognitive, informational, material and relational tasks delegated to patients/caregivers) and **capacity** (the affective, cognitive, informational, material and relational resources available to be mobilized by patients/caregivers). We then formulated simple explanatory propositions with which to characterise differences and similarities in treatment burden between conditions. These propositions, with coded data as supporting evidence, were used to develop a taxonomy which identifies and characterises primary and secondary constructs of BoT in lung cancer and COPD (Table 2).

Reflexivity:

As this was an interpretative synthesis, it was important to ensure that reflexivity was ongoing throughout the study. We did this first through discussions and reflections on the theoretical coding framework. Second, in discussions and reflections on extracted and coded data. Third, in reflections and discussions on the development of the simple explanatory propositions, supporting evidence for these and the development of the taxonomy.

Patient and public involvement:

Our wider National Institute for Health Research (NIHR) funded programme of research on complexity, patient experience and organisational behaviour has been developed in engagement with three groups in which more than 40 patients and caregivers have played a substantial role. In this particular study we worked closely with the late Mark Stafford-Watson (see acknowledgements). He played a valuable role in the development of the research question. Emerging results from this systematic review have been discussed with members of a local Breathe Easy (British Lung Foundation patient support group), and these discussions have informed the development of empirical research following the review

Results:

Characteristics of studies:

Figures 1 and 2 show each stage of the review process. We identified 127 articles: 85 COPD and 42 lung cancer. The papers included 1,233 COPD patients, 251 informal caregivers of COPD patients; 536 lung cancer patients and 240 informal caregivers of lung cancer patients. The majority of the papers were set in the UK, USA, Canada and

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Sweden. Ninety nine papers used qualitative interviews, 14 used interviews alongside either participant observation or focus groups. Eleven studies employed focus groups, two studies used case study and one study used serial dialogue. Further characteristics of studies are available in Appendix 3.

For ease of reference, we include a table with primary and secondary constructs (table 3).

Workload (primary construct):

Diagnosis (secondary construct):

For the majority of patients with COPD, the experience of receiving a diagnosis of COPD was not a memorable event (33-46) ; “a story without a beginning” (43). Often, patients had never received a formal diagnosis or were not informed of their diagnosis for many years. One study described how its participants questioned why they were recruited, unaware that they had been diagnosed with COPD (42). Even when given a diagnosis, many patients often did not understand the term ‘COPD’: “...as I say, I wasn’t even sure, it had never been put to me, formally put to me that I’d got this obstructive pulmonary or whatever they call it” (35) (p.706).

In contrast, patients with lung cancer almost universally described the moment of diagnosis as a “shock” (47-53), an unexpected and undesirable “crisis” which “flooded” patients’ lives (28). Patients felt overwhelmed by the existential threat of cancer that took away their ability to plan for or even imagine a future (48, 54, 55).

Illness identity (secondary construct):

Several studies demonstrated a lack of public understanding of COPD (33-35, 37, 39, 42, 43, 45, 56-59). Thus, patients and their informal caregivers often had not heard of

COPD prior to diagnosis and therefore had no expectations of the disease and its likely trajectory: "When cancer was excluded all worries about the future or fear of death fell away" (34) (p.558). Conversely, cancer has a recognisable public narrative, replacing tuberculosis as the disease the public most fears (60-63). In several of the studies, the patient's experience reflected this narrative shift (50, 53, 64): "Patients acknowledged despair...and some hoped for an alternative diagnosis: "It doesn't have to be lung cancer... it doesn't have to be the worst"" (64) (p.1207).

Attitude towards treatment (secondary construct):

Consequently, treatment for the illness – often became the overriding priority in life for patients with lung cancer (64-67), suspending the demands of everyday life: "Life is immediately put on hold...so a normal everyday life didn't concern me because everything revolved around treatment and only completion of the treatment was important so everything else didn't matter" (66) (p.5). Conversely, patients often saw COPD as a "way of life" (43) not an illness. The management and treatment of 'stable' COPD symptoms was seen as something that had to be integrated into everyday life rather than being a priority (35, 43, 57, 59, 68-73). Many patients with COPD, even with advanced illness, did not regard themselves as unwell (43, 59, 70, 71, 73). Patients reported exacerbations of COPD as 'proper' illnesses but saw the often debilitating symptoms of 'stable' COPD as a normal part of life, something to be accepted and coped with (70).

In the papers included, patients often described COPD as a "planning" disease, balancing the work of everyday life with the material demands of managing their treatment workload (42, 72, 74-79). This was complicated by the uncertainty of the illness trajectory making disease fluctuations difficult to anticipate and, consequently, to manage (33, 37, 39, 70, 80-84). Less commonly, patients with lung cancer also

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described the importance of planning and managing their own treatment workload (47, 66, 67, 85-87). More commonly, patients with lung cancer were overwhelmed by the debilitating pathophysiological side effects of their treatment such as breathlessness, fatigue, nausea and vomiting and were unable to focus on anything apart from treatment completion (48, 55, 65-67, 86, 88-92). Nonetheless, patients with lung cancer often experienced the practical demands of treatment – the treatment workload – as a relief, despite these potentially incapacitating pathophysiological side effects (51, 53, 86, 93). Patients repeatedly used the metaphor of treatment as “hope”, a lifebelt in the existential flood caused by the diagnosis of lung cancer (49, 51, 64, 86, 87, 91, 94, 95). Indeed, some patients reported a sense of “limbo” once the practical workload of treatment had finished (48, 66, 96-98). This “limbo” was both existential (66, 98): “Now I have lived for something, to complete and survive the treatment and suddenly the priority of life is gone” (66) (p.5) or structural, where patients felt in transition between healthcare institutions (48, 96, 97). Thus, paradoxically, patients with lung cancer could report a reluctance to stop treatment, despite its unpleasant pathophysiological side effects : “I’ll keep taking chemo as long as you’ll give it to me” (86) (p.105). Some patients with lung cancer also described continuing with treatment because they believed it was what their family wanted, rather than consulting their own preferences (67, 87, 99).

Patients with COPD reported how elements of treatment that supported self-management (for example, educational sessions at pulmonary rehabilitation (PR)) provided a much needed sense of control over their condition (35, 72, 78, 100-107). Yet, it was evident how fragile this sense of control might be, easily undermined by structural disadvantages such as transitions between healthcare institutions and lack of communication from and between HCPs (33, 37, 41, 58, 73, 108, 109):

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3 “I said, put them bloody tablets back [after one of usual medications stopped
4 in hospital, followed by him feeling unwell]. Don’t take stuff off me without telling
5 me. And I swore at him, [hospital doctor] I did, I was blazing. For giving me a
6 dodgy thing again. But that’s what you’ve got to put up with you see.” (41)
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15 This suggests unsupported and undermined self-management may be an exhausting
16 and frightening, rather than empowering experience for the patient and their informal
17 caregiver. Indeed, in the studies included, patients with COPD repeatedly describe the
18 relief of respite from the demands of self-management that institutionally provided
19 treatment (specifically hospitalization, PR, day hospice and specialist outpatient care)
20 brings (57, 58, 84, 104, 109-119):
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29 “Sometimes you can think, when you’re too sick, that they [medical staff] can
30 tell me what to do, so I don’t have to make all the decisions. I trust myself, but
31 it would be nice if someone just took care of me like that.” (111) (p.1485)
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37 However, particularly in the case of hospitalization, institutionally provided treatment
38 might also significantly add to the workload of patients with COPD. Patients reported
39 a hospital stay as a chaotic, confusing and disruptive experience. They felt they were
40 seen as “low priority” by the healthcare provider and frequently moved from ward to
41 ward (41, 79, 116, 120). Thus, some patients might try to avoid hospitalization (37, 41,
42 120).
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50 Identifying and accessing treatment options (secondary construct): 51

52 In the papers included, patients with lung cancer reported frequently having to make
53 decisions about whether or not to have treatment, which they repeatedly phrased as
54 a lack of choice: a choice between death or treatment (67, 91, 93, 97, 121). Whilst
55 ostensibly involved in the treatment decision-making process, some patients
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described having little real control over treatment options, believing they lacked the cognitive ability and specialist knowledge required to make informed treatment decisions (93, 97, 99). Indeed, frequently patients reported choosing to cede the cognitive burden of decision-making over treatment options to a trusted HCP (86, 93, 97, 99, 121, 122).

For patients with COPD, identification of treatment options could, itself, be problematic (35, 57, 70, 113, 123). Patients described being repeatedly told that “nothing could be done for them” by HCPs in both primary and secondary care (35, 57, 70, 113, 123). Thus, papers reported patients identifying treatment options from other sources of information such as the experience of peers or through their own research (56, 57, 68, 108, 113). Once treatment options were identified, patients could experience difficulty in accessing them (34, 35, 39, 40, 42, 44-46, 58, 70, 73, 74, 76, 103, 108, 109, 116, 120, 124-130).

Access to and navigation of healthcare institutions/systems (secondary construct):

After diagnosis, patients with lung cancer frequently reported rapid access to healthcare institutions and specialist HCPs who recognised and understood lung cancer and were able to co-ordinate its treatment workload (49, 67, 85, 121, 131, 132). Furthermore, patients with lung cancer appeared to follow a relatively structured treatment pathway (49, 53, 66, 67, 85, 121, 131, 132). In contrast, patients with COPD described encounters with gatekeeping generalist HCPs who did not recognise or understand their disease (44, 45, 58, 78, 109, 112, 113, 116, 124, 126, 129) and, consequently, significant delays in accessing specialist care. Patients with COPD reported the hard work of accessing healthcare, having to navigate between primary and secondary care, in a fragmented system, lacking a clear COPD treatment pathway (34, 37, 42, 44, 45, 58, 73, 74, 76, 103, 108, 109, 116, 120, 126, 127, 129).

Furthermore, patients described being expected to act as custodians of their own medical history, having to update HCPs with changes to their treatment (109, 133).

Practical workload of treatment (secondary construct):

Once treatment options were identified and accessed, patients with both conditions reported experiencing a significant practical workload, with multiple appointments for treatment, most commonly in hospitals for cancer (52, 91, 134) and occurring in a variety of settings for COPD (73, 101, 108, 120, 123, 125, 133, 135). Patients with both conditions described structural disadvantages such as the availability and cost of transportation and parking, physical restrictions in accessing healthcare (such as stairs), waiting for appointments and restricted time for appointments with HCPs that make their workload more onerous (34, 39, 42, 52, 58, 73, 91, 101, 108, 109, 120, 123, 125, 126, 129, 134, 135).

Patients with COPD and their informal caregivers reported being delegated a wide range of material treatment tasks by HCPs to self-manage at home. These included the management of complex medication regimens (33, 35, 42, 72, 74-76, 80, 109, 129, 130, 136), the operation of technologies such as oxygen (42, 45, 58, 59, 73, 79, 83, 106, 108, 109, 126, 127, 136-143), nebulisers (33, 68, 80, 126, 127, 140) and non-invasive ventilation (69, 144). These also included self-management of the illness itself: avoiding exacerbation triggers, monitoring physical symptoms and help-seeking when appropriate (35, 37, 68, 72-74, 76, 80, 103, 114, 130, 133, 145). In contrast, patients with lung cancer described receiving highly specialised, predominantly hospital-based therapies with little delegation of material treatment tasks (48, 50, 52, 53, 65-67, 86, 89, 91, 93, 97-99, 121, 131, 146). The exception was a study interviewing patients receiving oral targeted therapies who described the rigorous process they underwent when securing and taking medication (87). This paper

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highlighted the priority patients with lung cancer gave to their treatment because of the recognition of lung cancer’s immediate threat to life as they rigidly adhered to their delegated task (87).

Informational workload of treatment (secondary construct):

Patients with both conditions described being required to comprehend a large amount of information about their treatment (35, 37, 51, 56, 64, 66-68, 73, 83, 85, 88, 89, 94, 96, 97, 99, 103, 108, 121, 130, 132, 133, 136, 141, 147-150). Commonly, patients with lung cancer felt that high quality information about their treatment was available to them when they required it (64, 67, 85, 93, 97-99, 121, 132, 147, 148, 151). Nonetheless, the “shock” of diagnosis meant some patients struggled to retain or process information about treatment and therefore felt that further information was required once they began to assimilate their diagnosis (53).

Some patients with lung cancer wanted to be fully informed about their condition and treatment by their HCP, including prognosis, however bleak this was (67, 85, 98, 121, 132, 147, 148). In contrast, other patients found being fully informed overwhelming and frightening, particularly when given comprehensive written materials (53, 97, 147). They wanted limited information from HCPs, appearing to use this as a coping strategy to maintain hope for as long as possible, (48, 51, 64, 66, 97, 99, 121, 122, 152, 153) preferring not to be “frightened with too much...knowledge” (97) (p.969).

In a minority of cases, patients with lung cancer described information as not forthcoming when they wanted it and, as a consequence, felt ill-informed (94, 99, 122, 147). This was more frequently the case in patients with COPD. Patients often felt poorly informed about their condition and treatment at diagnosis and this continued throughout their disease trajectory (33-46, 74, 76, 78, 81, 108, 123, 127, 130, 133,

137, 154). This could be as fundamental as being given an inhaler without instructions on how to use it (42, 45).

Information could become a source of anxiety in both COPD and lung cancer when it was inconsistent or contradictory (36, 44, 56, 79, 89, 96-98, 109, 110, 122). Patients with lung cancer found the side effects of treatment about which they had not been informed, significantly more distressing than those symptoms about which they had been warned and therefore anticipated (88, 89).

Capacity (primary construct):

We found, in both conditions, capacity could be enhanced and/or, paradoxically, diminished following diagnosis.

Capacity enhanced following diagnosis:

Family and friends (secondary construct):

Patients with lung cancer and COPD repeatedly described family and friends as the main source of support for their treatment workload (37, 49, 55, 58, 66, 67, 73, 74, 76, 79, 80, 87, 108, 125, 130, 132, 147). Informal caregivers, like patients with lung cancer, prioritised the demands of treatment workload over the demands of everyday life and thus put their own life on hold:

Participants and carers described their ...life as inextricably tied to and affected by treatment patterns, appointments, complications and side effects. Additionally, the impact of various test results created a "scan by scan", "treatment cycle by cycle" or "suspended" approach to life, which had an impact not only for the patient but also carers and family. (67) (p.24)

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There could be an explicit recognition that this was possible owing to the short disease trajectory in lung cancer (54).

Informal caregivers’ participation in the treatment workload, whilst practically onerous, was often seen as an affirmation of the strength of their relationship with the patient (55, 66, 132, 151). This was echoed in many of the COPD studies (36, 73, 79, 80, 130). Indeed, there was a suggestion from some informal caregivers that the demands of the caring role deepened and enhanced their relationship with the patient over the protracted COPD disease trajectory (58, 74). Yet, still more studies demonstrate that informal caregivers felt “compelled” to take on a caring role rather than this being a conscious choice. Their identity imperceptibly and inexorably shifted from family member to caregiver (36, 37, 74, 76, 80, 130, 133, 136).The length of the disease trajectory in COPD meant that the informal caregiver, like the patient, had to balance the demands of treatment workload with the demands of everyday life (36, 74, 76, 130, 133, 136). The studies included repeatedly show that informal caregivers might find this practically limiting and affectively and cognitively demanding (36, 37, 69, 74, 76, 80, 83, 130, 133, 136, 137, 145).

Interestingly, despite the evidence of significant workload encountered by informal caregivers in COPD, it was patients with lung cancer who consistently described their fear of being a “burden” on their caregivers (49, 52, 54, 85, 86, 91, 95, 96, 99, 132, 147). This was less common in the COPD studies (42, 75, 101, 127), perhaps because the gradual development of the caring role over the long disease trajectory meant that the tasks the caregiver took on were not always obvious to the patient.

Health care professionals (secondary construct):

Patients with lung cancer frequently reported the importance of support from empathetic, trusted specialist HCPs in whom they had faith (49, 53, 66, 85-87, 93, 97, 121, 122, 131, 132). Patients with COPD also described positive experiences of interactions with HCPs (125, 129), particularly those with a specialist interest in COPD (57, 78, 80, 103, 106, 109, 120, 127) or those with whom they had relational continuity (80, 109, 125, 129). Patients with COPD described lack of relational continuity with HCPs as making access to, and navigation of, the healthcare system more challenging (81, 109, 111, 129). In a small minority of lung cancer cases, patients had lost confidence in their HCPs (85, 122). This loss of confidence in HCPs appeared more common in COPD (35, 38, 41, 44, 45, 73-76, 109, 113, 123, 126).

Peer support (secondary construct):

Patients with COPD appeared to benefit hugely from peer support (40, 68, 82, 108), which they generally accessed through PR (56, 57, 100-105, 107, 115, 135, 155). Peer support had both psychosocial benefits as patients felt less isolated (56, 100-102, 104, 105, 107, 115, 135) and practical benefits as a means of information-sharing about treatment options (56, 57). In contrast, there appeared to be little formal peer support accessed by patients with lung cancer. Interactions with other patients tended to be impromptu and often transitory (91, 97, 156) perhaps because of the typically short disease trajectory of lung cancer.

Disease trajectory (secondary construct):

Patients with COPD described a process of getting to know their bodies and symptoms over their long disease trajectory and, through a process of trial and error, being able to adapt and normalise treatments into their daily life (35, 37, 42, 68, 73, 103, 114, 150). Patients attending PR reported the importance of support to self-manage, and

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education and information about their condition from specialist HCPs (78, 101-106, 115). In contrast, patients with lung cancer described feeling ill-equipped to self-manage symptoms such as breathlessness at home, particularly in the earlier stages of treatment (92). This may be because the short disease trajectory of lung cancer does not allow patients to develop adequate self-management techniques and/or because patients/informal caregivers do not see self-management as appropriate or possible.

Capacity diminished following diagnosis:

Stigma (secondary construct):

Stigma occurs when society labels someone ‘tainted’ or ‘spoiled’ on the basis of an attribute that signals their difference to a societally perceived norm (157). Scambler (2008) usefully distinguishes between ‘enacted’ and ‘felt’ stigma (62). ‘Enacted’ stigma is actual discrimination by society against people with stigmatizing conditions. ‘Felt’ stigma is internalized stigma by people with stigmatizing conditions, manifesting itself as shame, guilt or blame or as fear of ‘enacted’ stigma.

In the papers included, patients with lung cancer and COPD frequently reported being considered culpable for their illness through smoking and consequently stigmatized by society (38, 40, 75, 113, 126, 151, 158). Patients with both conditions clearly internalized this stigma, repeatedly describing their diseases as “self-inflicted” (33, 35, 44, 75, 77, 79, 85, 101, 158-160). They experienced ‘felt’ stigma of self-blame, guilt and shame (38, 40, 44, 49, 75, 79, 85, 101, 145, 152, 158, 159). Some patients with COPD described how this internalized stigma led them to believe they do not deserve treatment (40, 101) : “I refused to go to the doctor. I thought it [COPD] was self-

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3 inflicted. If it's self-inflicted, why bother anyone?" (101) (p.314). Conversely, in the
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5 papers included, patients with lung cancer did not describe themselves as undeserving
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7 of treatment. Only one patient in one lung cancer study reported having to "endure"
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9 the unpleasant side effects of treatment because of his smoking history (147).

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11 Both COPD and lung cancer are not immediately visible to others. Patients reported
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13 how fear of 'enacted' stigma led them to conceal their illness identity (38, 40, 49, 152).
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15 Thus, patients with both conditions attempted to impose a "closed awareness context"
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17 (28), concealing their illness from all but a select few. Patients with both conditions
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19 also experienced the fear of 'enacted' stigma when 'marked' as unwell by their
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21 treatment (42, 87, 91, 137, 143). Hair loss caused by the side effects of lung cancer
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23 treatment is a clear signal of illness as is the ambulatory oxygen carried by some
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25 patients with COPD. In both conditions, therefore, the visible side effects of treatment
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27 or technologies may disrupt the "closed awareness context" (28) patients have
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29 carefully maintained around their illness identity, leading to patients avoiding social
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31 situations and, consequently, social isolation (42, 126)

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33 Patients with COPD often described feeling stigmatized by their HCPs (39, 40, 44, 71,
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35 74, 75, 118, 126-128). Patients with COPD and their informal caregivers felt that HCPs
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37 believed that patients who had smoked were not entitled to treatment or gave
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39 substandard treatment to (ex) smokers (39, 75, 126, 128):

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41 "Well, the care from Father's doctors was extremely basic and, I felt, on the
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43 most part extremely uncaring...The doctors really had an attitude of 'You were
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45 a smoker, you're dying of lung disease, and what do you want us to do about
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47 it" (36) (p.161).

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Consequently, patients were reluctant to access treatment for fear of such enacted stigma (38, 40). Several papers reported the difficulties of accessing treatment for patients who had smoked (36, 75, 126, 128). One study described an extreme example of HCP stigma where the authors argue that patients receiving non-invasive ventilation, an unpleasant treatment for exacerbations of COPD, experienced this as a “punishment” for their “self-inflicted” disease (118).

In contrast, in the studies included, patients with lung cancer did not describe encountering stigmatizing attitudes from HCPs. Only one patient in one study was concerned that their care would be affected because of the links the disease had to smoking (158).

Social isolation (secondary construct):

Self imposed social isolation:

Frequently, patients with lung cancer and COPD experienced social isolation because of their illness (36, 37, 42, 53, 66, 74, 76-80, 82, 96, 101, 102, 111, 114, 126, 127, 133, 136, 139, 143, 145, 156, 161, 162). This might be self-imposed because of embarrassment about visible symptoms (such as breathlessness and cough), medications (such as inhalers) or health technologies (such as oxygen) that mark patients as ill and therefore expose them to the threat of enacted stigma (42, 77, 87, 90, 91, 137, 142, 143). Additionally, in COPD, self-imposed isolation was also used as a self-management technique to avoid exacerbation triggers (such as the risk of infection from crowds) (76, 111).

Involuntary social isolation:

Social isolation might likewise be involuntary in both lung cancer and COPD as friends withdrew and social networks contracted (50, 53, 82, 101, 136, 143, 156). Patients

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3 reported feeling “contagious” (50)(p.734), (136)(p. 145). In both conditions, social
4
5 isolation was also a result of common psychological comorbidities such as depression,
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7 low mood and anxiety following diagnosis leading to avoidance of social situations (53,
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9 78, 79, 82, 101, 102, 156).

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13 Patients with COPD reported that the practical and logistical challenges of the
14
15 treatment workload itself (for example, the weight of portable oxygen cylinders, the
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17 fear of running out of oxygen while waiting for appointments, having complex
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19 technologies such as non-invasive ventilation at home) further added to involuntary
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21 social isolation (38, 42, 58, 59, 69, 73, 79, 108, 111, 126, 137, 139-141, 143). In
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23 COPD, involuntary social isolation also appeared to worsen with disease progression
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25 and the consequent relentless deterioration of physical function (37, 74, 80, 82, 127,
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27 139, 161, 162). This clearly extended beyond the patient to affect the informal
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29 caregiver as their responsibilities increased with the pathophysiological decline of the
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31 patient (36, 37, 74, 76, 80, 133, 136). In the papers included, there were fewer
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33 accounts of this from patients with lung cancer, perhaps because of the typically short
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35 disease trajectory (96).
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44 Discussion:

45 46 47 48 49 Illness as agent; patient as agent:

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51 The overriding discourse evident throughout the lung cancer studies is that of ‘illness
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53 as agent’. Patients with lung cancer, informal caregivers and HCPs immediately
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55 recognise lung cancer as an existential threat. In order to stave off death, the
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57 significant demands of treatment workload become the overriding life priority in what
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59 is typically a short illness trajectory. Patients with lung cancer have to undergo a
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gruelling treatment workload in secondary care, with potentially debilitating pathophysiological side effects but limited delegated tasks from HCPs. This workload is generally well supported by an immediacy of access to healthcare institutions and specialist HCPs and a typically clear and structured treatment pathway. Patients with lung cancer often regard the practicalities of the treatment workload as a relief from the cognitive burden the existential threat of their illness identity has imposed. Patients and informal caregivers use the simile of “treatment as hope” and may be reluctant to stop treatment, despite potentially devastating side effects.

Conversely, the recurrent theme throughout the COPD studies is that of ‘patient as agent’. Patients do not recognise or understand their illness and therefore do not consider it a terminal disease. Consequently, the demands of treatment workload are balanced with the domestic, professional and sentimental demands of the workload of everyday life throughout the typically long illness trajectory. Patients with COPD are delegated a wide range of highly complex treatment tasks by HCPs to self-manage at home. This workload may be made more onerous by difficulties of access to, and navigation of, primary and secondary healthcare systems, generalist professional gatekeepers who lack understanding of COPD and a fragmented treatment pathway that does not meet the needs of home-based self-management. Synthesis of patient and informal caregiver accounts demonstrates that poorly supported self-management is hard, unrelenting work for patients with COPD and their informal caregivers. Patients and their informal caregivers can build up strategies over time to self-manage their condition more effectively, particularly when supported by healthcare provision such as PR. Nonetheless, pathophysiological deterioration and increasingly complex management and treatment regimens mean that the demands of the treatment workload over the long disease trajectory accumulate. Thus,

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3 institutionalized care that temporarily relieves patients and informal caregivers of the
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5 practical, affective and cognitive workload of self-management may be seen as a
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7 welcome respite from self-management. Yet patients with COPD often lack access to
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9 such specialist, institutionalized care, especially at the end of life (163, 164)
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13 Social skill, capital and structural resilience: 14

15 Patients with lung cancer and COPD are typically able to draw on the support of family
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17 and friends which enhances their social skill (the extent to which they are able to
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19 secure the co-operation and co-ordination of others) and social capital (their ability to
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21 access informational and material resources), bolstering their structural resilience
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23 (their potential to absorb adversity) (1). Like patients themselves, informal caregivers
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25 of patients with lung cancer recognise cancer's existential threat and prioritise
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27 supporting the treatment workload over the demands of everyday life. This support
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29 can be a cathartic and life-enhancing process for patients and informal caregivers
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31 alike. While this can also apply in COPD, informal caregivers often lack choice in taking
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33 on the caregiving role, describing an inexorable process of accumulating responsibility
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35 over the long disease trajectory as patients' functional performance deteriorates. In
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37 lung cancer, informal caregivers may also lack choice in taking on the caregiving role
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39 but the disease trajectory (and thus the caring trajectory) is shorter.
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46 The "weaker ties" (165) of peer support are extremely important in enhancing the
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48 social skill and capital of patients with COPD and bolstering structural resilience. In
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50 lung cancer, because of its high mortality and short disease trajectory, patients are
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52 less likely to need peer support, or indeed, be able to access it as their peers die
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54 around them.
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Illness related and especially smoking related ‘felt’ and ‘enacted’ stigma degrade the social skill and capital of patients with both conditions. The invisibility of both conditions, unless ‘marked’ by treatment means that patients may attempt to conceal their condition, leading to social isolation. Social isolation is increased by the psychosocial impact of diagnosis and pathophysiological deterioration caused by both illness and the side effects of treatments. Stigma and social isolation and the consequent loss of opportunities to use social skill and access capital, reduces the structural resilience of patients with both conditions.

Strengths and limitations:

This systematic review and qualitative synthesis differs from previous reviews on BoT. BoT has been examined generally across many conditions (2, 12), with capacity considered specifically (3). Other systematic reviews are condition specific: heart failure (8, 10) and stroke (9). Yet more consider treatment burden in multiple chronic conditions: diabetes, chronic kidney disease and heart failure (6) and chronic kidney disease, heart failure and COPD (166). This review, like May et al (166), considers patient and caregiver interactions with health care services in order to characterise treatment burden but identifies primary qualitative papers rather than systematic reviews and meta-syntheses.

To the best of our knowledge, this review is the first to explicitly compare BoT in malignant and non-malignant disease. As such, it offers a novel review which synthesises patient and informal caregiver perspectives on burden of treatment in malignant and non-malignant disease across a range of healthcare systems and settings. It identifies and characterises BoT in lung cancer and COPD through the development of a taxonomy (Table 2). This has important implications both for researchers seeking to understand BoT and for clinicians, as they seek to ameliorate

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2
3 the impact of treatment on respiratory patients and their informal caregivers. We have
4 made recommendations for clinical practice which can be found in Table 4.
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8 The heterogeneity of the papers included is both a strength and limitation of this
9 synthesis. The heterogeneity of papers means uniformities identified through the
10 taxonomy should facilitate the development of an explanatory model of burden of
11 treatment (167). However, the taxonomy has been developed from descriptions of
12 patient experience *taken out of context*. It describes the generalities of patient
13 experience across multiple healthcare systems and settings, rather than considering
14 factors such as socioeconomic status and the attributes of healthcare systems that
15 have been shown to be important in the consideration of BoT (1). Furthermore,
16 qualitative research is, necessarily, interpretative and therefore the data analysed,
17 whilst ostensibly from primary sources, are seen through the multiplicity of theoretical
18 lenses chosen by the studies' authors and their varying epistemological and
19 ontological stances. Finally, this paper itself uses an interpretative framework for
20 synthesis and therefore results are refracted through the authors' own lenses.
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39 We limited our search to publications between January 2006- December 2015 as we
40 intended to identify burden of treatment in COPD and lung cancer with the aim of
41 informing *current* health care practice and policy. In their discussion of the
42 methodological challenges of reviewing patient experience of treatment burden in
43 stroke, Gallacher et al (7) highlight how the management of chronic disease has
44 changed dramatically in recent years. We believed it was important, therefore, that
45 pertinent (and thus more recent) literature was identified and reviewed to ensure that
46 patient experience of treatment burden was based on current rather than historical
47 healthcare practices. The systematic review took some time to undertake and write
48 up, hence publications after December 2015 are not included which is a limitation.
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We excluded studies that were not in peer reviewed journals (i.e. grey literature) and studies that are not in the English language because of resource constraints which could be regarded as a limitation.

What is not in the literature:

The studies identified focus almost exclusively on the index conditions of lung cancer and COPD. Studies focus on lung cancer or COPD, whereas many patients may have both lung cancer and COPD (168).They do not discuss the issue of multimorbidity which is common in both conditions (169) (170) and is likely to have a significant impact on BoT (4).

Conclusions:

This interpretative synthesis of qualitative literature on patient/informal caregiver interactions with healthcare in lung cancer and COPD demonstrates that the workload of treatment may be very different in each condition. The socio-cultural status of cancer as one of the most feared of all diseases (60, 61) means that ‘illness is agent’. Thus, lung cancer patients are required to subordinate the demands of everyday life to the demands of the treatment workload. Patients have little choice but to follow a structured treatment pathway, in healthcare systems that generally meet the needs of their typically short diseases trajectory. Conversely, in COPD, patients are expected to exert agency over their own condition, “empowered” to self-manage, integrating the demands of the treatment workload into their everyday life. Patients have to identify their own treatment pathway, navigating between institutions, in healthcare systems that are not set up to meet the needs of their uncertain and often lengthy disease trajectory. The differences in the treatment workload of lung cancer and COPD identified by this synthesis resonate with other qualitative studies comparing cancer

with other chronic conditions (predominantly heart failure but also COPD and motor neurone disease) (61, 171, 172).

Despite the differences of the treatment workload between conditions, this interpretative synthesis has demonstrated the importance of the personal and collective capacity available to patients and their informal caregivers in both conditions, suggesting that a workload which exceeds capacity is likely to be a primary driver of treatment burden.

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Table 1: Inclusion/exclusion criteria for systematic review

Inclusion criteria	Exclusion criteria
Participants: aged >18, diagnosed with lung cancer or COPD, or their informal caregivers	Reports: of treatment effectiveness, for example RCTs; reports of healthcare provision which are not focused on patients' or informal caregivers' experiences; qualitative studies which focus only on professional experience, or report secondary analyses, or review or synthesise data; editorials, notes, letters and case reports; protocols of qualitative studies
Reports: results of primary qualitative studies of patients' or informal caregivers' experiences of interactions with health and social care services published in peer reviewed journals	Insufficient data to answer research question
Settings: healthcare systems in Europe (excluding Turkey), North America and Australia	
Date of publication: between 1 January 2006 and 31 December 2015	
Language: English	

Table 2. Taxonomy of treatment burden in lung cancer and COPD.

PRIMARY CONSTRUCT	SECONDARY CONSTRUCT	LUNG CANCER	REFERENCES	COPD	REFERENCES
Workload (the affective, cognitive, informational, material and relational tasks delegated to patients/care givers)	Diagnosis /illness identity	Diagnosis as shock	47-55	Diagnosis imperceptible	33-46
		Obvious illness identity with socio-cultural resonance (therefore understood by patient/informal caregiver/HCP)	50, 53, 64	Unclear illness identity, without socio-cultural resonance (therefore poorly understood by patient/informal caregiver/HCP)	33-35, 37, 39, 42, 43, 45, 56-59
		Short disease trajectory (clear to patient and informal caregiver)	50, 53, 64	Long and uncertain disease trajectory (unclear to patient and informal caregiver)	33-35, 37, 39, 42, 43, 45, 56-59
	Attitude towards treatment	Demands of treatment workload as overriding life priority (for both patient and informal caregiver)	64-67	Demands of treatment workload balanced with domestic/professional/sentimental demands of everyday life (for both patient and informal caregiver)	35, 43, 57, 59, 68-73
		Practical demands of treatment workload as a relief from the existential threat of cancer	51, 53, 86, 93	Practical demands of treatment workload as hard work	33, 37, 39, 42, 70, 72, 74-84
		Treatment as hope	49, 51, 64, 86, 87, 91, 94, 95	Institutionalized care as respite from unrelenting	57, 58, 84, 104, 109-119

		Sense of 'limbo' once treatment completed	48, 66, 96-98	demands of self-management	
		Reluctance to stop treatment despite debilitating pathophysiological side effects	86		
		Treatment for family rather than for patient	67, 87, 99		
	Treatment options	Lack of options: treatment or death	67, 91, 93, 97, 121	Lack of treatment options (lack of information or feeling that 'nothing can be done' from HCPs)	35, 57, 70, 113, 123
		Decision to cede control over choice of treatment options to trusted HCPs	86, 93, 97, 99, 121, 122		
	Access to/navigation of healthcare system/Institutions	Immediacy of access to healthcare	49, 67, 85, 121, 131, 132	Difficulties with access to healthcare	44, 45, 58, 78, 109, 112, 113, 116, 124, 126, 129
		Specialist HCPs with specific knowledge of lung cancer	49, 67, 85, 121, 131, 132	Generalist HCPs who lack specific knowledge of COPD	44, 45, 58, 78, 109, 112, 113, 116, 124, 126, 129
		Structured treatment pathway	49, 53, 66, 67, 85, 121, 131, 132	Fragmented treatment pathway	34, 37, 42, 44, 58, 73, 74, 76, 103, 108, 109, 116, 120, 126, 127, 129
	Practical workload of treatment	Specialist treatment workload in secondary care with debilitating pathophysiological side effects	52, 91, 134	Multiple appointments for treatment in primary, secondary care and in the community	73, 101, 108, 120, 123, 125, 133, 135

		Limited delegated tasks from HCPs	48, 50, 52, 53, 65-67, 86, 89, 91, 93, 97-99, 121, 131, 146	Significant workload of delegated treatment tasks at home from HCPs	33, 35, 37, 42, 45, 58, 59, 68, 69, 72-76, 79, 80, 83, 103, 106, 108, 109, 114, 126, 127, 129, 130, 133, 136-145
	Informational workload of treatment	Generally high quality information provided in written form and from specialist HCPs	64, 67, 85, 93, 97-99, 121, 132, 147, 148, 151	Patients typically poorly informed about condition from diagnosis to death adding to treatment workload	33-46, 74, 76, 78, 81, 108, 123, 127, 130, 133, 137, 154
		Lack of information as a deliberate choice on the part of patients – a tactic for maintaining hope in the face of a poor prognosis	48, 51, 64, 66, 97, 99, 121, 122, 152, 153	Conflicting/contradictory information adds to patient/informal caregiver distress	36, 44, 56, 79, 109, 110,
		Conflicting/contradictory information adds to patient/informal caregiver distress	89, 96-98, 122		
Capacity (the affective, cognitive, informational, material and relational resources available to be mobilized by	Family and friends	Family and friends are seen as the main source of support post diagnosis (but fear of being a 'burden' on family)	49, 55, 66, 67, 87, 132, 147 'Burden' : 49, 52, 54, 85, 86, 91, 95, 96, 99, 132, 147	Family and friends are seen as the main source of support post diagnosis	37, 58, 73, 74, 76, 79, 80, 108, 125, 130

patients/care givers) - Enhanced by diagnosis		Family and friends are able to prioritise supporting the patient through their treatment workload owing to the short disease trajectory and the recognition of the patient's likely imminent death	54	Family and friends have to balance the demands of the treatment workload with the demands of everyday life owing to the long and uncertain disease trajectory	36, 74, 76, 130, 133, 136
		Support for the patient's treatment workload seen as an affirmation of the strength of the patient/family member relationship in the face of imminent death	55, 66, 132, 151	Support for the patient's treatment workload may be seen as an affirmation of the strength of the patient/family member relationship	36, 58, 73, 74, 79, 80, 130
				Caregivers feel compelled to take on a care-giving role over the long duration of the disease trajectory	36, 37, 74, 76, 80, 130, 133, 136
	Healthcare professionals	Importance of support from empathetic, trusted HCPs in whom patients have faith	49, 53, 66, 85-87, 93, 97, 121, 122, 131, 132	Importance of support from trusted HCPs, especially those with specialist knowledge of COPD	57, 78, 80, 103, 106, 109, 120, 125, 127, 129
		Less commonly, loss of faith in HCPs	85, 122	Importance of relational continuity with HCPs making access to and navigation of the healthcare system and its institutions easier	80, 81, 109, 111, 125, 129

				Loss of faith in HCPs	35, 38, 41, 44, 45, 73-76, 109, 113, 123, 126
	Peer support	Little peer support available for patients with lung cancer. What is available appears impromptu and transitory	91, 97, 156	Peer support is an important resource and is generally accessed through pulmonary rehabilitation	40, 68, 82, 108 PR: 56, 57, 100-105, 107, 115, 135, 155
				Shared experiences with peers reduces isolation	56, 100-102, 104, 105, 107, 115, 135
				Peer support is used as a resource for information sharing	56, 57
	Disease trajectory	Short disease trajectory: ill equipped to self manage symptoms at home	92	Long disease trajectory: get to know their bodies and symptoms, through trial and error	35, 37, 42, 68, 73, 103, 114, 150
Capacity (the affective, cognitive, informational, material and relational resources available to be mobilized by patients/care givers) - Diminished by diagnosis	Stigma	Patients are considered culpable for their illness and stigmatized by society	151, 158	Patients are considered culpable for their illness and stigmatized by society	38, 40, 75, 113, 126
		Patients consider themselves culpable for their illness: a "self-inflicted" disease	85, 159, 160	Patients consider themselves culpable for their illness: a "self-inflicted" disease	33, 35, 44, 75, 77, 79, 101, 161
		Patients experience 'felt' stigma of blame, guilt and shame	49, 85, 152, 158, 159	Patients experience 'felt' stigma of blame, guilt and shame	38, 40, 44, 75, 79, 101, 145
		Patients attempt to conceal their	49, 152	Patients attempt to conceal their	38, 40

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		condition owing to fear of 'enacted' stigma leading to social isolation		condition owing to fear of 'enacted' stigma leading to social isolation	
		Patients feel 'marked' by visible treatment leading to social isolation	87, 91	Patients feel 'marked' by visible treatment leading to social isolation	42, 126, 137, 143
				Patients internalize stigma, considering themselves undeserving of treatment	40, 101
				Patients experience 'enacted' stigma from HCPs, making access to treatment challenging	36, 38, 39, 40, 44, 71, 74, 75, 118, 126-128
	Social isolation (Self-imposed)	Embarrassment about symptoms, medications and treatment technologies which mark the patient as ill leading to fear of 'enacted' stigma	87, 90, 91	Embarrassment about symptoms, medications and treatment technologies which mark the patient as ill leading to fear of 'enacted' stigma	42, 77, 137, 142, 143
				Exacerbation triggers – leads to avoidance of social situations	76, 111
	Social isolation (Involuntary)	Illness as contagious: social networks contract as friends withdraw	50, 53, 156	Illness as contagious: social networks contract as friends withdraw. Isolation worsens with disease progression and deterioration of	82, 101, 136, 143 Deterioration: 37, 74, 80, 82, 127, 139, 161, 162

				physical function	
		Psychological co-morbidities lead to avoidance of social situations	53, 156	Logistical difficulties of treatment workload limits patient to home	38, 42, 58, 59, 69, 73, 79, 108, 111, 126, 137, 139- 141, 143
				Social isolation extends beyond patient to affect informal caregiver	36, 37, 74, 76, 80, 133, 136
				Psychological co-morbidities lead to avoidance of social situations	78, 79, 82, 101, 102

Table 3: Primary/secondary constructs

PRIMARY CONSTRUCT	SECONDARY CONSTRUCT
Workload (the affective, cognitive, informational, material and relational tasks delegated to patients/caregivers)	Diagnosis/illness identity
	Attitude towards treatment
	Treatment options
	Access to/navigation of healthcare system/institutions
	Practical workload of treatment
	Informational workload of treatment
Capacity (the affective, cognitive, informational, material and relational resources available to be mobilized by patients/caregivers) - Enhanced by diagnosis	Family and friends
	Healthcare professionals
	Peer support
	Disease trajectory
Capacity (the affective, cognitive, informational, material and relational resources available to be mobilized by patients/caregivers) - Diminished by diagnosis	Stigma
	Social isolation (self-imposed)
	Social isolation (involuntary)

Table 4: Recommendations for clinical practice

RECOMMENDATIONS FOR CLINICAL PRACTICE:
Patients living with respiratory disease and their informal caregivers may experience treatment as hard work. Equally, patients and caregivers may see treatment as ‘hope’ and therefore be reluctant to stop.
Patients’ capacity to undertake the treatment workload may be enhanced and/or diminished by diagnosis. Consideration should be given to the volume of treatment workload delegated to the patient/informal caregiver and their capacity undertake this workload. Clinicians could use the taxonomy (table 2) to aid and support consideration and discussion of workload and capacity.

Legend:

Figure 1: PRISMA flowchart for COPD articles

sFigure 2: PRISMA flowchart for lung cancer articles

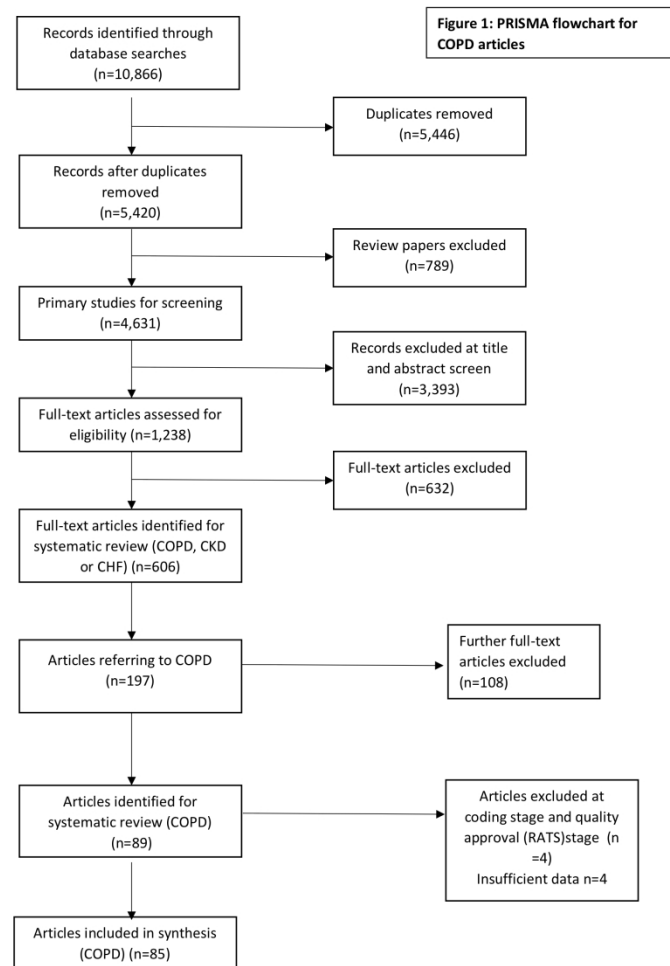


Figure 1: PRISMA flowchart for COPD articles

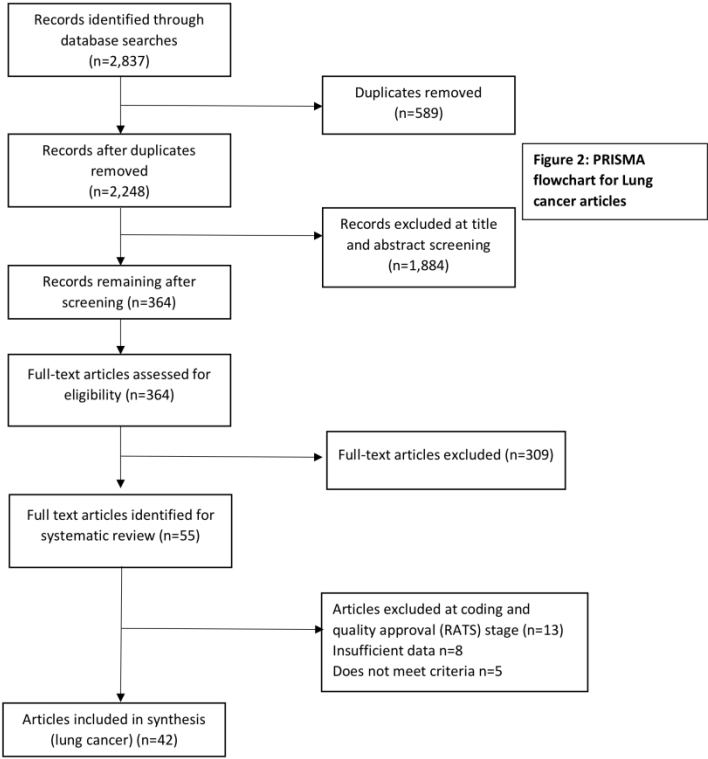


Figure 2: PRISMA flowchart for lung cancer articles

Appendix 1: MEDLINE SEARCH STRATEGY. OVID INTERFACE.

CHF/CKD/COPD:

- 1 Heart Failure/
- 2 heart failure, diastolic/ or heart failure, systolic/
- 3 ((heart\$1 or cardiac or cardial or myocardial) adj3 failure\$1).ti,ab,kf.
- 4 ((heart\$1 or cardiac or cardial or myocardial) adj3 decompensat\$).ti,ab,kf.
- 5 ((heart\$1 or cardiac or cardial or myocardial) adj3 incompetenc\$).ti,ab,kf.
- 6 ((heart\$1 or cardiac or cardial or myocardial) adj3 insufficienc\$).ti,ab,kf.
- 7 ((heart\$1 or cardiac or cardial or myocardial) adj3 (standstill or stand-still)).ti,ab,kf.
- 8 (CHF or CHF\$).ti,ab,kf.
- 9 or/1-8
- 10 exp Renal Insufficiency, Chronic/
- 11 Renal Insufficiency/
- 12 exp Renal Replacement Therapy/
- 13 Hemodialysis Units, Hospital/
- 14 (chronic kidney or chronic renal or chronic nephropath\$).ti,ab,kf.
- 15 (kidney failure\$1 or renal failure\$1).ti,ab,kf.
- 16 (renal insufficienc\$ or kidney insufficienc\$).ti,ab,kf.
- 17 (dialysis or predialysis).ti,ab,kf.
- 18 (hemodialysis or haemodialysis).ti,ab,kf.
- 19 (hemofiltration or haemofiltration).ti,ab,kf.
- 20 (hemodiafiltration or haemodiafiltration).ti,ab,kf.
- 21 (end-stage renal or end-stage kidney or endstage renal or endstage kidney).ti,ab,kf
- 22 (stage 5 and (renal disease\$1 or kidney disease\$1)).ti,ab,kf.
- 23 (kidney transplant\$ or renal transplant\$ or kidney graft\$ or renal graft\$ or kidney replacement\$1 or renal replacement\$1).ti,ab,kf.
- 24 (CKF or CKD or CRF or CRD).ti,ab,kf.
- 25 (ESKD or ESRD or ESKF or ESRF).ti,ab,kf.
- 26 (CAPD or CCPD or APD).ti,ab,kf.
- 27 or/10-26
- 28 exp Pulmonary Disease, Chronic Obstructive/
- 29 (obstruct\$ adj3 (pulmonary or lung\$1 or airway\$1 or airflow\$1 or bronch\$ or respirat\$)).ti,ab,kf.
- 30 (chronic\$ adj3 bronchiti\$).ti,ab,kf.
- 31 emphysem\$.ti,ab,kf.
- 32 (COPD or COAD or COBD or AECB).ti,ab,kf.
- 33 or/28-32
- 34 9 or 27 or 33
- 35 exp qualitative research/
- 36 qualitativ\$.ti,ab,kf.
- 37 interviews as topic/
- 38 interview\$.ti,ab,kf.
- 39 focus groups/
- 40 focus group\$1.ti,ab,kf.
- 41 grounded theory/ or (grounded theor\$ or grounded study or grounded studies or grounded research or grounded analys\$).ti,ab,kf.
- 42 phenomenol\$.ti,ab,kf.
- 43 (ethnograph\$ or ethnonurs\$ or ethno-graph\$ or ethno-nurs\$).ti,ab,kf.

44 (story or stories or storytelling or narrative\$1 or narration\$1).ti,ab,kf.
 45 (open-ended or open question\$ or text\$).ti,ab,kf.
 46 Narration/ or personal narratives/ or personal narratives as topic/
 47 (discourse\$ analys\$ or discours\$ analys\$).ti,ab,kf.
 48 content\$ analys\$.ti,ab,kf.
 49 ethnological.ti,ab,kf.
 50 purposive sampl\$.ti,ab,kf.
 51 (constant comparative or constant comparison\$1).ti,ab,kf.
 52 theoretical sampl\$.ti,ab,kf.
 53 (theme\$ or thematic\$).ti,ab,kf.
 54 (emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$).ti,ab,kf.
 55 data saturat\$.ti,ab,kf.
 56 participant observ\$.ti,ab,kf.
 57 exp Humanism/ or (humanistic\$ or existential\$ or experiential\$ or
 paradigm\$).ti,ab,kf.
 58 Postmodernism/ or (social construct\$ or postmodern\$ or post-modern\$ or
 poststructural\$ or post-structural\$ or feminis\$ or constructivis\$).ti,ab,kf.
 59 (action research or cooperative inquir\$ or co-operative inquir\$).ti,ab,kf.
 60 human science.ti,ab,kf.
 61 biographical method\$.ti,ab,kf.
 62 life world.ti,ab,kf.
 63 theoretical saturation.ti,ab,kf.
 64 group discussion\$1.ti,ab,kf.
 65 direct observation\$.ti,ab,kf.
 66 mixed method\$.ti,ab,kf.
 67 (observational method\$ or observational approach\$).ti,ab,kf.
 68 key informant\$1.ti,ab,kf.
 69 (field study or field studies or field research\$ or field work\$ or fieldwork\$).ti,ab,kf.
 70 (semi-structured or semistructured or unstructured or un-structured or informal or
 in-depth or indepth).ti,ab,kf.
 71 "face-to-face".ti,ab,kf.
 72 ((guide or structured) adj5 (discussion\$1 or questionnaire\$1)).ti,ab,kf.
 73 (heidegger\$ or colaizzi\$ or speigelberg\$ or van manen\$ or van kaam\$ or merleau
 ponty\$ or husserl\$ or giorgi\$ or foucault\$ or corbin\$ or glaser\$).ti,ab,kf.
 74 or/35-73
 75 Consumer Behavior/
 76 attitude/ or exp attitude to health/ or Attitude to Death/
 77 personal satisfaction/
 78 exp Emotions/
 79 Stress, psychological/
 80 exp Patients/px
 81 Caregivers/px
 82 professional-patient relations/ or nurse-patient relations/ or physician-patient
 relations/
 83 professional-family relations/
 84 Empathy/
 85 Feedback/
 86 ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or
 caregiver\$1 or care-giver\$ or family\$1 or families) and (experient\$ or perspective\$1
 or perception\$1 or opinion\$1 or account or accounts or attitude\$1 or view or views

or viewpoint\$1 or satisf\$ or unsatisf\$ or dissatisf\$ or disatisf\$ or belief\$1 or believ\$)).ti.

87 ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or care-giver\$ or family\$1 or families) adj3 (experient\$ or perspective\$1 or perception\$1 or opinion\$1 or account or accounts or attitude\$1 or view or views or viewpoint\$1 or satisf\$ or unsatisf\$ or dissatisf\$ or disatisf\$ or belief\$1 or believ\$)).ab,kf.

88 ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or care-giver\$ or family\$1 or families) and (emotion\$ or feeling\$1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet\$ or anxious\$ or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat\$ or stress\$ or distress\$ or embarrass\$ or empath\$ or accept\$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother\$ or unbother\$ or pleased or displeased\$ or concern\$ or burden\$ or hassl\$ or convenien\$ or inconvenien\$ or confus\$ or hope or hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or confiden\$ or unconfiden\$)).ti.

89 ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or care-giver\$ or family\$1 or families) adj3 (emotion\$ or feeling\$1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet\$ or anxious\$ or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat\$ or stress\$ or distress\$ or embarrass\$ or empath\$ or accept\$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother\$ or unbother\$ or pleased or displeased\$ or concern\$ or burden\$ or hassl\$ or convenien\$ or inconvenien\$ or confus\$ or hope or hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or confiden\$ or unconfiden\$)).ab,kf.

90 (life experience\$1 or lived experience\$1 or actual experience\$1 or real experience\$1).ti,ab,kf.

91 or/75-90

92 34 and 74 and 91

93 ((heart\$1 or cardiac or cardial or myocardial) adj3 (failure\$1 or decompensation or incompetenc\$ or insufficienc\$ or standstill or stand-still)).ti.

94 (CHF or CHF\$).ti.

95 (kidney or renal or nephropath\$ or dialysis or predialysis or hemodialysis or haemodialysis or hemofiltration or haemofiltration or hemodiafiltration or haemodiafiltration or CKF or CKD or CRF or CRD or ESKD or ESRD or ESKF or ESRF or CAPD or CCPD or APD).ti.

96 (obstruct\$ adj3 (pulmonary or lung\$1 or airway\$1 or airflow\$1 or bronch\$ or respirat\$)).ti.

97 (chronic\$ adj3 bronchiti\$).ti.

98 emphysem\$.ti.

99 (COPD or COAD or COBD or AECB).ti.

100 or/93-99

101 qualitativ\$.ti. or qualitative research/

102 ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or care-giver\$ or family\$1 or families) and experiences).ti.

103 ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or care-giver\$ or family\$1 or families) adj2 experienc\$).ti.

104 100 and (101 or 102 or 103)

105 92 or 104

106 exp animals/ not humans/

107 (news or comment or editorial or letter or case reports or randomized controlled trial).pt.

108 case report.ti.

109 105 not (106 or 107 or 108)

110 limit 109 to (english language and yr="2006 -Current")

111 remove duplicates from 110

Lung cancer:

1. exp Lung Neoplasms/

2. Carcinoma, Non-Small-Cell Lung/

3. Small Cell Lung Carcinoma/

4. (lung adj2 cancer\$).ti,ab,kf.

5. 1 or 2 or 3 or 4

6. exp Qualitative Research/

7. qualitativ\$.ti,ab,kf.

8. Interviews as Topic/

9. interview\$.ti,ab,kf.

10. Focus Groups/

11. focus group\$1.ti,ab,kf.

12. Grounded Theory/

13. (grounded theor\$ or grounded study or grounded studies or grounded research or grounded analys\$).ti,ab,kf.

14. phenomenol\$.ti,ab,kf.

15. (ethnograph\$ or ethnonurs\$ or ethno-graph\$ or ethno-nurs\$).ti,ab,kf.

16. (story or stories or storytelling or narrative\$1).ti,ab,kf.

17. (open-ended or open question\$ or text\$).ti,ab,kf.

18. Narration/

19. Personal Narratives/

20. Personal Narratives as Topic/

21. (discourse\$ analys\$ or discours\$ analys\$).ti,ab,kf.

22. content\$ analys\$.ti,ab,kf.

23. ethnological.ti,ab,kf.

24. Purposive sampl\$.ti,ab,kf.

25. (constant comparative or constant comparison\$1).ti,ab,kf.

26. theoretical sampl\$.ti,ab,kf.

27. (theme\$ or thematic\$).ti,ab,kf.

28. (emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$).ti,ab,kf.

29. data saturat\$.ti,ab,kf.

30. participant observ\$.ti,ab,kf.

31. exp Humanism/
32. (humanistic\$ or existential\$ or experiential\$ or paradigm\$).ti,ab,kf.
33. Postmodernism/
34. (social construct\$ or postmodern\$ or post-modern\$ or poststructural\$ or post-structural\$ or feminis\$ or constructivis\$).ti,ab,kf.
35. (action research or cooperative inquir\$ or co-operative inquir\$).ti,ab,kf.
36. human science.ti,ab,kf.
37. biographical methods\$.ti,ab,kf.
38. life world.ti,ab,kf.
39. theoretical saturation.ti,ab,kf.
40. mixed method\$.ti,ab,kf.
41. (observational method\$ or observational approach\$).ti,ab,kf.
42. key informant\$1.ti,ab,kf.
43. (field study or field studies or field research\$ or field work\$ or fieldwork\$).ti,ab,kf.
44. (semi-structured or semistructured or unstructured or un-structured or informal or in-depth or indepth).ti,ab,kf.
45. "face-to-face".ti,ab,kf.
46. ((guide or structured) adj5 (discussion\$1 or questionnaire\$1)).ti,ab,kf.
47. (heidegger\$ or colaizzi\$ or speigelberg\$ or van manen\$ or van kaam\$ or merleau ponty\$ or husserl\$ or giorgi\$ or foucault\$ or corbin\$ or glaser\$).ti,ab,kf.
48. 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47
49. Consumer Behavior/
50. Attitude/
51. exp Attitude to Health/
52. Attitude to Death/
53. Personal Satisfaction/
54. exp Emotions/
55. Stress, Psychological/
56. exp Patients/px [Psychology]
57. Caregivers/px [Psychology]
58. Professional-Patient Relations/
59. Nurse-Patient Relations/
60. Physician-Patient Relations/
61. Professional-Family Relations/
62. Empathy/
63. Feedback/
64. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or family\$1 or families) and (experient\$ or perspective\$1 or perception\$1 or opinion\$1 or account or accounts or attitude\$1 or view or views or

viewpoint\$1 or satisf\$ or unsatisf\$ or dissatisf\$ or disatisf\$ or belief\$1 or believ\$)).ti.

65. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or family\$1 or families) adj3 (experienc\$ or perspective\$1 or perception\$1 or opinion\$1 or account or accounts or attitude\$1 or view or views or viewpoint\$1 or satisf\$ or unsatisf\$ or dissatisf\$ or disatisf\$ or belief\$1 or believ\$)).ab,kf.

66. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or family\$1 or families) and (emotion\$ or feeling\$1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet\$ or anxious\$ or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat\$ or stress\$ or distress\$ or embarrass\$ or empath\$ or accept\$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother\$ or unbother\$ or pleased or displeased\$ or concern\$ or burden\$ or hassl\$ or convenien\$ or inconvenien\$ or confus\$ or hope or hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or confiden\$ or unconfiden\$)).ti.

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73. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal or carer\$1 or caregiver\$1 or care-giver\$ or family\$1 or families) and experiences).ti.

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80. case-report.ti.

81. 77 not (78 or 79 or 80)

82. limit 81 to (english language and yr="2006 -Current")

For peer review only

Appendix 2. Quality assessment tool (modified RATS)

Reference number/ Reviewer initials	Criteria	Detail	Yes/No
	Relevance	<ul style="list-style-type: none">• Is the research question clearly stated?• Is the question generated from an analysis of the literature?	
	Appropriateness of method	<ul style="list-style-type: none">• Is the qualitative method(s) stated most effective way of addressing the research question?• Is it stated why this method was used?	
	Transparency of research procedures	<ul style="list-style-type: none">• Is the sampling procedure explained?• Are the criteria for the selection of participants stated?• Was the collection of data systematic and comprehensive?• Is the role of the researchers addressed?• Are ethical issues addressed?	
	<p>Soundness of interpretive approach</p> <p>Presentation of findings and common features of poor research</p>	<ul style="list-style-type: none">• Is the analytical approach a reasonable approach and judged to be appropriate for the study?• Are the interpretations clearly outlined and supported by empirical evidence?• Were the interpretations checked?• Are the findings embedded in a theoretical or conceptual framework?• Is the way that the results add to existing knowledge stated?• Are limitations stated?• Is the article well written?• Is there an overuse of jargon?• Do the interpretations seem appropriate? Are they self-evident?• Is there an adequate discussion of consent – thin detail often indicates poor ethics.	

Appendix 3: full characteristics of included studies

COPD

Study	Year	Country	Qualitative method	Index condition	Setting	How sampled?	Sample	Age of sample	Gender of sample	How data analysed?	Study details
Adams et al #157	2006	UK, Netherlands, Denmark	Interviews	COPD	Community	Convenience	23 patients	38-84	16M, 7F	Descriptive (thematic analysis)	To explore the notion of COPD exacerbations from the viewpoint of patients who had recently suffered an exacerbation.
Arnold, E. #165	2011	UK	Interviews	COPD	Community	Purposive	27 patients	54-85	14M, 13F	Theory building (grounded theory)	To obtain in-depth information about perceptions and use of prescribed ambulatory oxygen systems from patients with COPD to inform ambulatory oxygen design, prescription and management.
Arnold, E. #166	2006	UK	Interviews	COPD	Pulmonary rehabilitation (hospital based)	Participants screened against eligibility criteria. All eligible patients invited to participate. Participants recruited until no new themes emerged.	20 patients	45-85	9M, 11F	Theory building (grounded theory)	To explore the experiences of COPD patients invited to join a pulmonary rehabilitation programme.
Boyle, Anne H.#9	2009	USA	Interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	10 wives	57-71	10F	Theory informed (phenomenological-hermeneutic approach)	To describe and understand meaning of experience of living with a spouse who has COPD

Caress, A.#170	2010	UK	Interviews	COPD	Acute hospital	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	14 patients, 12 family members	Patients = 60-80. Family members not stated	Patients = 8M, 6F. Family members = 3M, 9F	Descriptive (content analysis)	To generate in-depth insights into patients' and family members' understanding of the causation, progression and prevention of COPD and the role of health promotion with this population
Clancy, Karen #13	2009	UK	Serial interviews	COPD	Acute hospital	Participants screened against eligibility criteria. Those eligible who agreed to participate included. Informal care-givers nominated by patients.	9 patients, 7 care-givers	Patients = 57-78. Care-givers = 50-78	Patients = 6M, 3F. Care-givers = 2M, 5F	Theory informed (phenomenological-hermeneutic approach)	To explore the existential experiences of patients with COPD who had been prescribed long-term oxygen therapy and their carers
Clarke, A #14	2010	UK	Interviews	COPD	Community	Purposive (maximum variation)	23 patients	50-80	14M, 9F	Theory building (grounded theory)	To explore patients' views of an early supported discharge service for COPD
Cooke, M #15	2012	UK	Focus groups	COPD	Community	Purposive	8 HCPs, 30 patients, 2 care-givers	Patients = 48-73. Care-givers and HCPs not stated	Patients = 16M, 15F. Care-givers = 2F. HCPs not stated	Descriptive (thematic analysis)	To define, compare and order 'assessed needs and defined outcomes' of professional providers of COPD services with patients' 'prioritised needs and defined outcomes' and relate these to service provision

Curry, R. #172	2006	UK	Interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	11 patients	Not stated	Not stated	Descriptive (thematic framework approach)	To explore patients' views of introduction of a new nurse-led urgent care team (UCT) for patients with COPD
Dickenson, J.#19	2009	UK	Interviews	COPD	Community	Participants screened against eligibility criteria.	12 patients	Not stated	Not stated	Descriptive (framework approach)	To explore the COPD patient's perception of their dietary habits and nutritional status and to identify their perceptions of dietary health and its impact on general quality of life.
Ehrlich, Carolyn #22	2010	Australia	Interviews	COPD	Community	Theoretical sampling	9 patients	56-77	4M, 5F	Theory building (grounded theory)	To report how people with COPD gather, interpret and apply health affecting information
Ek, K.#23	2014	Sweden	Interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible, who agreed to participate included.	13 family members	Not stated	7M, 6F	Descriptive (content analysis)	To retrospectively describe the final year of life for patients with advanced COPD with a focus on death and dying from the perspective of relatives.
Ek, K.#24	2011	Sweden	Serial interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	4 patients	66-75	1M, 3F	Theory informed (phenomenological-hermeneutic approach)	To describe the experience of living with advanced COPD and long-term oxygen therapy when living alone

Ek, K.#25	2008	Sweden	Interviews	COPD	Hospital	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	8 patients	48-79	3M, 5F	Theory informed (phenomenological approach)	To describe the essential structure of the lived experience of living with severe COPD during the palliative phase of the disease
Ek, K.#26	2011	Sweden	Serial interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	4 couples (4 patients, 4 spouses)	67-74	4M, 4F	Theory informed (phenomenological-hermeneutic approach)	To examine couples' experiences of living together when one partner has advanced COPD
Ellison, L.#27	2012	UK	Interviews	COPD	Community	Convenience and purposive	14 patients	49-79	7M, 7F	Descriptive (constant comparison and framework approach)	To understand the mental health needs of people living with COPD
Fischer, M. J #31	2007	Netherlands	Interviews	COPD	Pulmonary rehabilitation (outpatient)	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	12 patients	34-77	8M, 4F	Theory informed (interpretative phenomenological analysis)	To examine patients' pre-treatment beliefs and goals regarding pulmonary rehabilitation
Fraser, D. D.#34	2006	USA	Interviews	COPD	Community	Purposive	10 patients	59-86	5M, 5F	Theory informed (phenomenological-hermeneutic approach)	To understand how COPD affects the lives of patients.
Gale, N. K.#36	2015	UK	Interviews	COPD	Community	Purposive	20 patients, 4 carers, 15 HCPs	Patients = 52-83. Carers not stated. HCPs = 26-54	Patients = M = 8, F = 12. Carers and HCPs not stated.	Theory building (grounded theory)	To explore experiences of domiciliary non-invasive ventilation in COPD, to understand decision-making processes and improve future palliative care

Goodridge, D #41	2011	Canada	Interviews	COPD and bronchiectasis	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	7 patients	57-88	2M, 5F	Descriptive (interpretive description)	To explore the impact of living with advanced chronic respiratory illness in a rural area
Gullick, J #45	2008	Australia	Serial Interviews	COPD	Community	Convenience	15 patients, 14 family members	Patients = 55-77. Family members = 29-82	Patients = 9M, 6F. Family members not stated	Theory informed (phenomenological-hermeneutic approach)	To explore the experience of the person who lives within a body with COPD
Guo, S.E. #161	2014	Canada	Interviews and focus groups	COPD	Pulmonary rehabilitation (outpatient)	Patients screened against eligibility criteria. Those eligible who agreed to participate included. HCPs sampled purposively.	25 patients, 7 HCPs	Patients = 53-84. HCPs not stated.	Patients = 13M, 12F. HCPs not stated.	Descriptive (thematic analysis)	To describe the experiences of patients who are in a pulmonary rehabilitation (PR) programme and explore the perceptions of patients and HCPs about what improves effective PR
Gysels #48	2008	UK	Interviews and participant observation	COPD	Community and outpatient clinics	Purposive	18 patients	52-78	7M, 11F	Theory building (grounded theory)	To explore the experience of breathlessness in patients with COPD through patients' accounts of their interactions with services
Gysels #178	2010	UK	Interviews and participant observation	COPD	Community and outpatient clinics	Purposive	18 patients	Median 69/70	7M, 11F	Descriptive (narrative analysis)	To investigate how the experience of breathlessness in COPD influences patients' attitudes toward the end of life and their quality of life

Habraken #49	2008	Netherlands	Interviews	COPD	Outpatient clinics and respiratory centre	Purposive	11 patients	61-83	8M, 3F	Descriptive (thematic analysis)	To gain insight into why patients with end-stage COPD tend not to express a wish for help
Halding #50	2012	Norway	Serial interviews	COPD	Pulmonary rehabilitation (outpatient)	Purposive (maximum variation)	18 patients	52-81	13M, 5F	Descriptive (thematic analysis)	To explore the experience of patients with COPD in terms of their transitions in health during and after pulmonary rehabilitation
Hall #53	2010	Canada	Interviews	COPD	Acute hospital	Patients screened against eligibility criteria.	6 patients	Mean age 69	4M, 2F	Descriptive (exploratory descriptive)	To describe the perceptions of people living with severe COPD with respect to the end of life
Harris #55	2008	UK	Interviews	COPD	Community	Purposive	16 patients	Mean age 66.8	12M, 4F	Theory building (grounded theory)	To assess patients' concerns about accepting an offer of pulmonary rehabilitation
Hasson #58	2009	Canada	Interviews	COPD	Community	Care-givers screened against eligibility criteria. Those eligible who agreed to participate included.	9 care-givers	25-65	2M, 7F	Descriptive (content analysis)	To explore the experiences of palliative care that bereaved carers had while providing care to a dying loved one with COPD
Hasson #57	2008	UK	Interviews	COPD	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	13 patients	45-65	10M, 3F	Descriptive (content analysis)	To explore the potential for palliative care among people living with COPD

Hayle #59	2013	UK	Interviews	COPD	Specialist palliative care	Participants recruited against eligibility criteria. Those eligible who agreed to participate included.	8 patients	63-77	5M, 3F	Theory informed (phenomenological-hermeneutic approach)	To evaluate the experiences of patients with COPD who accessed palliative care
Hellem #61	2012	Norway	Interviews and focus groups	COPD	Pulmonary rehabilitation (outpatient)	Purposive	11 patients	53-68	3M, 8F	Theory informed (phenomenological approach)	To elucidate how patients with COPD who successfully maintain a long term exercise programme understand concordance with maintenance exercise and see potential solutions
Hogg, L. #62	2012	UK	Focus groups	COPD	Pulmonary rehabilitation (outpatient)	Purposive	16 patients	Patients divided into two groups. Group 1 = 71 (mean). Group 2 = 67 (mean)	9M, 7F	Theory building (grounded theory)	To understand the views and perceptions of patients with COPD regarding maintaining an active lifestyle following a course of pulmonary rehabilitation
Hopley, #63	2009	New Zealand	Interviews	COPD	Community	Purposive	9 patients	50-80	Not stated	Descriptive (general inductive approach)	To understand the challenges people living with COPD in rural areas face in accessing specialist health care services
Hynes, G #65	2012	Ireland	Interviews	COPD	Community	Patients identified care-givers. All invited to participate. Owing to small numbers, further recruitment in patient support groups and advertisements in media.	11 care-givers	20-79	2M, 9F	Descriptive (thematic analysis)	To explore the experiences of informal caregivers providing care in the home to a family member with COPD

Jackson, #66	2012	Canada	Case study	COPD	Community	Convenience	4 patients	57-81	3F, 1M	Descriptive (thematic analysis)	To understand older patients with COPD experiences of their journeys through the health system
Jonsdottir #71	2007	Iceland	Serial interviews	COPD	Community	Convenience	7 patients	40-65	7F	Theory informed (interpretive phenomenology)	To explore the experience of women with advanced COPD of repeatedly relapsing to smoking
Kanervisto #72	2007	Finland	Interviews	COPD	Hospital	Participants selected by clinicians	5 patients, 4 spouses	Not stated	Patients = 3M, 2F. Spouses = 3F, 1M	Descriptive (deductive content analysis)	To describe the coping of the families of people with advanced COPD
Kauffman, #73	2014	USA	Focus groups	COPD	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	18 patients	49-75	12M, 6F	Descriptive (thematic analysis)	To describe the subjective sleep complaints of patients with COPD along with their attributions as to the cause of these symptoms and their treatment preferences for insomnia
Keating #74	2011	Australia	Interviews	COPD	Pulmonary rehabilitation (outpatient)	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	37 patients	53-86	18M, 19F	Descriptive (thematic analysis)	To understand what prevents people with COPD from attending and completing pulmonary rehabilitation
Kerr #75	2010	UK	Interviews	COPD	Pulmonary rehabilitation (outpatient)	All patients attending pulmonary rehabilitation invited to participate. Those who agreed to participate accepted on study.	9 patients	62-80	6M, 3F	Theory building (grounded theory)	To understand from an occupational perspective how patients live with COPD

Kvangarsnes #77	2013	Norway	Interviews	COPD	Acute hospital	Purposive	10 patients	45-85	5M, 5F	Descriptive (narrative analysis)	To explore patient perceptions of COPD exacerbation and experiences of their relations with health personnel during care and treatment
Lewis #79	2014	UK	Interviews	COPD	Pulmonary rehabilitation (community)	Convenience	25 patients	42-90	Not stated	Theory informed (interpretative phenomenological approach)	To explore the lived experience of COPD patients referred to pulmonary rehabilitation programmes prior to participation
Lewis #80	2010	UK	Focus group	COPD	Community	Purposive	6 patients	61-83	1M, 5F	Descriptive (thematic analysis)	To explore the attitudes of people with COPD to exercise and reasons for non-concordance with exercise maintenance post pulmonary rehabilitation
Lindgren #81	2014	Norway	Interviews	COPD	Community	Purposive	8 patients	60-74	3M, 5F	Theory informed (phenomenological-hermeneutic approach)	To illuminate patients' lived experiences of being diagnosed with COPD
Lindqvist #82	2013	Sweden	Serial interviews	COPD	Community	Purposive	21 spouses	53-84	21F	Theory informed (phenomenography)	To describe the conceptions of daily life in women living with a man suffering from COPD in different stages

Lindqvist #83	2010	Sweden	Serial interviews	COPD	Acute hospital	Open sampling initially then theoretical sampling in order to saturate emerging categories	23 patients	52-82	10M, 13F	Theory building (grounded theory)	To illuminate the main concern of patients with COPD and how they handle their everyday life
Lindqvist #159	2013	Sweden	Serial interviews	COPD	Community	Purposive	19 spouses	55-85	19M	Theory informed (phenomenography)	To describe the conceptions of daily life in men living with a woman suffering from COPD in different stages
Lomborg, K.#86	2008	Denmark	Participant observation and interviews	COPD	Acute hospital	Patients screened against eligibility criteria and consecutively included. Further sampling selective and theoretical.	12 patients, 4 HCPs	Patients = >30. HCPs not stated	Not stated	Theory building (grounded theory)	To explore COPD patients' and nurses' expectations, goals and approaches to assisted personal body care.
Lundh, L. #87	2012	Sweden	Interviews	COPD	Community	Participants screened against eligibility criteria and recruited consecutively.	14 patients	47-83	7M, 7F	Theory building (grounded theory)	To investigate why some patients with COPD have difficulty quitting smoking and to develop a theoretical model that describes their perspectives on these difficulties.
Luz, E. L #88	2013	Portugal	Interviews	COPD	Community	Convenience and theoretical sampling	22 patients	26-72	17M, 5F	Theory building (grounded theory)	To understand how people live with COPD

MacPherson, A. #89	2013	UK	Interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	10 patients	58-86	9M, 1F	Theory building (grounded theory)	To explore the views of people with severe COPD about advance care planning
Mathar, H. #90	2015	Denmark	Interviews	COPD	Community	Purposive	6 patients	67-83	3M, 3F	Descriptive (text condensation method)	To understand the experiences and preferences of COPD patients in relation to discharge from hospital with televideo consultations
McMillan Boyles, C #93	2011	Canada	Interviews	COPD	Community	Purposive	15 patients	>50	Not stated	Descriptive (narrative analysis)	To develop an understanding of the meaning of disability for individuals living with COPD
Meis, J #94	2014	Netherlands	Interviews and focus groups	COPD	Pulmonary rehabilitation (inpatient)	Patients screened against eligibility criteria. Those eligible who agreed to participate included. HCPs randomly invited to participate.	13 patients, 14 HCPs	Patients = 54 -78. HCPs = 24-52	Patients = 8M, 5F. HCPs = 3M, 11F	Theory informed (descriptive phenomenological approach)	To assess COPD patients' experiences during an inpatient pulmonary rehabilitation program
Moore, #96	2012	UK	Interviews	COPD	Pulmonary rehabilitation (community)	Random sampling of three groups meeting different eligibility criteria. Patients recruited until data saturation had been achieved.	24 patients	47-84	14M, 10F	Descriptive (framework approach)	To assess the obstacles to participation in pulmonary rehabilitation among COPD patients in a community based pulmonary rehabilitation programme and associated general practices

Mousing #97	2012	Denmark	Interviews and focus groups	COPD	Community	Interviews: participants screened against eligibility criteria and then consecutively recruited until recruitment target met. Focus group: all participants attending patient education sessions invited to participate.	11 patients	51-75	3M, 8F	Descriptive (thematic analysis)	To explore how group patient education influences the self-care of patients with COPD
Nykvist #100	2014	Sweden	Interviews	COPD	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	6 patients	Not stated	6F	Descriptive (narrative analysis)	To describe how a group of smoking women with COPD experienced their everyday life and their relationship to smoking
Panos #107	2013	USA	Focus groups	COPD	Community	Participants were selected by systematic sampling against eligibility criteria and consecutively recruited until recruitment target met.	42 patients	48-88	42M	Descriptive (thematic analysis)	To determine the perceptions of veterans with COPD about their disease, its effects on their lives and their interactions with the Veterans' Healthcare Administration
Philip #108	2012	Australia	Interviews and focus groups	COPD	Acute hospital	Patients screened against eligibility criteria. Patients recruited consecutively until data saturation had been achieved. HCPs sampled purposively.	10 patients, 31 HCPs	Patients = 55-76. HCPs = 23-61	Patients = 6M, 4F. HCPs not stated	Descriptive (thematic analysis)	To explore the views of patients with COPD and HCPs focusing upon information needs and treatment preferences

Philip #109	2014	Australia	Interviews	COPD	Community	Care-givers identified by patient or physician. Those who agreed to participate included in study.	19 care-givers	28-83	9M, 10F	Descriptive (thematic analysis)	To understand the experiences and needs of family carers of people with severe COPD
Pinnock #110	2011	UK	Serial interviews and focus groups	COPD	Community	Purposive	21 patients, 13 care-givers, 18 HCPs	Patients = 50-83. Care-givers and HCPs not stated.	Patients = 14M, 7F. Care-givers and HCPs not stated.	Descriptive (thematic narrative analysis)	To understand the perspectives of patients with severe COPD as their illness progresses, and of their informal and professional carers
Reinke #112	2008	USA	Serial interviews	COPD or cancer	Community	HCPs: Drs screened against eligibility criteria, classified into specialty categories and then randomly selected. Nurses identified by patients or drs. Patients: identified by HCPs against eligibility criteria. Relatives: identified by patients.	55 patients, 56 HCPs, 36 relatives	Patients = 67.3 (mean), relatives = 60.3 (mean), HCPs = 47 (mean)	Patients = 22M, 33F. Relative s = 18M, 18F. HCPs = 22M, 34F	Theory building (grounded theory)	To examine participants' perspectives on the experiences of key transitions in the context of living with advanced COPD or cancer
Schroedl #117	2014	USA	Interviews	COPD	Acute hospital	Purposive	20 patients	52-83	9M, 11F	Descriptive (thematic analysis)	To understand the unmet health care needs among patients to help determine which aspects of palliative care are most beneficial

Seamark #119	2012	UK	Interviews	COPD	Community	Patients screened against eligibility criteria. All eligible patient invited to participate.	16 patients	58-83	12M, 4F	Descriptive (content analysis and constant comparison)	To examine whether an admission to hospital for an exacerbation of COPD is an opportunity for advance care planning (ACP) and to understand, from a pt perspective, the optimum circumstance for ACP
Sheridan #121	2011	New Zealand	Interviews	COPD	Community	Pragmatic (8 patients initially interviewed, further participants from a certain ethnic group recruited in order to explore theme further)	29 patients	50-89	15M, 14F	Descriptive (thematic analysis)	To explore how patients with COPD experience helplessness
Shipman #122	2009	UK	Interviews	COPD	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included. 4 patients excluded post interview as did not meet eligibility criteria.	16 patients	54-86	9M, 7F	Descriptive (framework approach)	To explore factors that influence the use of general practice services by people with advanced COPD
Shum #123	2014	Canada	Interviews and focus groups	COPD	Community	Convenience	30 patients, 16 care- givers	Not stated	Not stated	Descriptive (thematic analysis)	To investigate how patients with COPD from new immigrant communities received and utilised information about their condition and its management

Simpson #125	2010	Canada	Interviews	COPD	Community	Purposive	14 care-givers	46-89	3M, 11F	Descriptive (interpretive description)	To understand the extent and nature of 'burden' experienced by informal care-givers in advanced COPD
Simpson #156	2012	Canada	Serial dialogue	COPD	Community	Participants screened against eligibility criteria.	8 patients , 8 care-givers	Patients = 53-76. Care-givers not stated.	Patients = 4M, 4F. Care-givers = 3M, 5F	Descriptive (interpretive description)	To understand what is required for meaningful and effective advance care planning in the context of advanced COPD
Small #191	2012	UK	Interviews and focus groups	COPD	Community	Patients screened against eligibility criteria then randomly selected and invited to participate. Those eligible who agreed to participate included. Staff recruited from primary and secondary care with range of staff characteristically involved in COPD care (drs and nurses)	21 patients , 39 HCPs	Patients = 57-78. HCPs = 25-63	Split site study. Only one set of patients/H CPs reported on. Patients = 7M, 6F. HCPs = 6M = 6; F = 14	Descriptive (thematic analysis)	To report patients, family members and HCPs' experiences of COPD
Sorensen #128	2013	Denmark	Participant observation , interviews	COPD	Acute hospital	Participants screened against eligibility criteria. Those eligible who agreed to participate included. Recruitment continued until conceptual density achieved.	21 patients (obs) 11 patients (ints)	43-81	11M, 10 F	Theory building (grounded theory)	To present a theoretical account of the pattern of behaviour in patients with acute respiratory failure owing to COPD while undergoing non-invasive ventilation

Sossai #129	2011	Australia	Interviews	COPD	Community	Purposive	8 patients	50-85	5M, 3F	Descriptive (thematic analysis)	To explore the experience of living with COPD
Spence #130	2008	UK	Interviews	COPD	Community	Purposive	7 care-givers	55-65	1M, 6F	Descriptive (content analysis similar to constant comparison)	To explore the specific care needs of informal care-givers of patients with advanced COPD
Strang #133	2013	Sweden	Interviews	COPD	Community	Purposive (maximum variation)	31 patients	48-85	15M, 16F	Descriptive (thematic content analysis)	To explore perceptions of anxiety and the alleviation strategies that are adopted by patients with COPD
Thorpe #137	2014	Australia	Interviews	COPD	Hospital	Purposive	28 patients	Mean age 71.86	22M, 6F	Descriptive (content analysis)	To explore the barriers to and enablers of participation in physical activity following hospitalisation for COPD
Torheim #138	2010	Norway	Interviews and focus groups	COPD	Acute hospital	Purposive	5 patients , 8 nurses	Patient s = 45-78. Nurses not stated.	Patients = 2M, 3F. Nurses not stated.	Theory informed (phenomenological approach)	To explore the experiences of mask treatment in patients with acute exacerbations of COPD
Torheim #139	2014	Norway	Interviews	COPD	Acute hospital	Strategic (recruited to meet eligibility criteria)	10 patients	45-85	5M, 5F	Theory informed (phenomenological approach: meaning condensation)	To gain insight how patients with advanced COPD experience care in the acute phase (specifically in the intensive care unit)

Willgoss #145	2012	UK	Interviews	COPD	Community	Purposive (nonprobabilistic)	14 patients	Mean age 62.3	5M, 9F	Descriptive (thematic network analysis)	To elicit and describe the first-hand experiences of anxiety in community patients with stable COPD
Williams #147	2010	UK	Interviews	COPD	Pulmonary rehabilitation (outpatient)	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	9 patients	54-84	6M, 3F	Theory building (grounded theory)	To explore how pulmonary rehabilitation affects the experience of activity and breathlessness of people with COPD
Williams #146	2007	UK	Interviews	COPD	Community	Purposive	6 patients	64-83	4M, 2F	Descriptive (thematic analysis)	To investigate what is most important to people living with COPD
Williams #148	2011	UK	Interviews	COPD	Community	Purposive and theoretical sampling	18 patients	54-84	12M, 6F	Theory building (grounded theory)	To understand how people with COPD experience activity
Wilson #150	2008	Canada	Serial interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	12 patients	Not stated	Not stated	Descriptive (constant comparison approach)	To determine the care needs of seniors living at home with advanced COPD
Wilson #152	2007	UK	Focus groups	COPD	Community	Purposive	32 patients, 8 HCPs	Patients = 56-82. HCPs not stated.	Patients = 25M, 7F. HCPs not stated	Theory building (grounded theory)	To ascertain what should be included in the educational component of pulmonary rehabilitation
Wodsku #153	2014	Denmark	Interviews and focus groups	COPD	Community	Purposive	34 patients, 8 relatives	Patients = 48-87; Relatives = not stated	Patients = 15M, 9F. Relatives = 3M, 5F	Descriptive (content analysis)	To examine the experiences of COPD patients and their relatives of integrated care

LUNG CANCER

Author	Year	Country	Qual method	Index condition	Setting	How sampled?	Sample	Age of sample	Gender of sample	How data analysed?	Study details
Amichai #3	2012	Canada	Interviews	Lung cancer	Acute hospital	Purposive	12 patients	40-70	6M, 6F	Descriptive (interpretative)	To understand lung cancer patients' beliefs about complementary and alternative medicine use in promoting their own wellness
Arber #226	2013	UK	Interviews	Lung cancer	Acute hospitals	Theoretical sampling until data saturation achieved	10 patients	56-82	8M, 2F	Theory building (grounded theory)	To explore patients' experience during the first 3 months following a diagnosis of malignant pleural mesothelioma
Baker #8	2012	UK	Interviews	Breast, lung or prostate cancer	Acute hospitals	Purposive. Recruitment continued until theoretical saturation reached.	42 patients	36-86	23M, 19F	Descriptive (constant comparison technique)	To investigate the readiness of patients to address emotional needs up to 18 months following a diagnosis of cancer
Bertero #11	2008	Sweden	Interviews	Lung cancer	Acute hospitals	Purposive	23 patients	36-86	12M, 11F	Theory informed (phenomenological-hermeneutic approach)	To describe how having inoperable lung cancer affects the patients' life situation and quality of life
Brown #300	2015	Australia	Interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	10 patients	50-89	8M, 2F	Theory building (grounded theory)	To explore the supportive care needs and preferences of lung cancer patients
Carrion #16	2013	USA	Interviews	Lung, brain, colorectal, prostate cancer	Community	Purposive	15 patients (2 living with lung, 2 brain, 2 colorectal, 9 prostate)	31-71	15M	Descriptive (thematic analysis)	To explore beliefs and treatment decisions of Latino men with cancer

Caughlin #160	2011	USA	Interviews	Lung cancer	Community	Participants recruited by advertisement and screened against eligibility criteria. Those who agreed to participate, included.	35 family members	36-72	6M, 29F	Theory building (grounded theory)	To examine families' communication and coping in response to a parent's lung cancer
Dale #161	2011	UK	Interviews	Lung cancer	Palliative care	Purposive	6 patients	67-81	2M, 4F	Descriptive (thematic analysis)	To explore the concerns of patients with inoperable lung cancer
Dorman #112	2009	UK	Interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included. Recruitment continued until no new themes emerged.	9 patients	Not stated	5M, 4F	Theory informed (Interpretative Phenomenological Analysis)	To study what patients with recently diagnosed brain metastases from NSCLC want from their treatment
Epiphaniou #270	2014	UK	Serial interviews	Lung cancer and COPD	Acute hospital	Purposive	18 patients (11 living with lung cancer, 7 COPD)	52-90	12M, 6F	Descriptive (thematic analysis)	To explore patients' experience of care coordination in COPD and lung cancer
Eustache #271	2014	Canada	Interviews	Lung cancer	Cancer centre	Purposive (maximum variation)	12 patients	36-78	6M, 6F	Descriptive (interpretative)	To explore the experience and meaning of hope in relation to the healing process of patients living with lung cancer
Farley #349	2015	UK	Interviews	Lung cancer	Acute hospital	Purposive	22 patients	39-82	12M, 10F	Descriptive (framework approach)	To explore lung cancer patients' views about smoking and about their preferences for support to help them quit

Gerber #195	2012	USA	Focus groups	Lung cancer	Cancer centre/acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	13 patients	39-69	7M, 6F	Descriptive (thematic content analysis)	To gain insight into patients' perceptions of maintenance chemotherapy
Hamilton #135	2010	USA	Focus groups	Lung, colon, breast, other cancer	Outpatient oncology clinics	Purposive. Recruitment continued until theoretical saturation reached.	22 patients (4 living with lung, 9 breast, 2 colon, 7 other)	50-80	7M, 15F	Theory building (grounded theory)	To explore the perceived social support needs among older African American cancer survivors
Hendriksen #312	2015	USA	Interviews	Lung cancer	Cancer centres	Patients screened against eligibility criteria. Caregivers nominated by patient and screened against eligibility criteria.	11 patients, 10 caregivers	Patients = 36-78. Caregivers = 34-74	Patients = 8F, 3M. Caregivers = 5F, 5M	Theory building (grounded theory)	To explore the nature of shared anxiety and its impact on patient-caregiver dyads
Hoff #64	2014	Sweden	Serial interviews	Malign haematological disease or lung cancer	Acute hospitals	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	12 patients (5 living with lung, 7 haematological)	37-80	5M, 7F	Descriptive (content analysis)	To identify challenges in communicating with patients with lung cancer about their imminent death
Hoffman #276	2014	USA	Focus groups	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	6 patients	53-73	2M, 4F	Descriptive (directed content analysis)	To identify the postsurgical NSCLC patients' unmet supportive care needs during transition from hospital to home

Horne #50	2006	UK	Interviews	Lung cancer	Community	Purposive	9 patients	52-87	3M, 6F	Theory building (grounded theory)	To develop and pilot an advance care planning intervention for lung cancer nurses
Horne #200	2012	UK	Interviews	Lung cancer	Cancer centres	Purposive	25 patients, 19 family members	47-85 (patients). Family members not stated	18M, 7F. Family members not stated.	Theory building (grounded theory)	To explore the views and experiences of people affected by lung cancer about discussing preferences and wishes for end of life care and treatment
John #141	2010	USA	Interviews	Lung cancer	Cancer centres	Purposive	10 patients	48-87	6M, 4F	Descriptive (content analysis)	To describe self care strategies used by patients with lung cancer to promote quality of life
Krishnasamy #68	2007	UK	Serial interviews	Lung cancer	Cancer centres	Participants screened against eligibility criteria. Those eligible, who wished to participate, included. Recruitment continued until data saturation achieved.	60 patients, 31 family members	Patients = 38-82. Family members not stated.	Patients = 32M, 28F. Family members = 4M, 27F	Theory building (grounded theory)	To explore the experiences of care provision of patients with lung cancer and their carers
Lee #120	2009	Australia	Case study report	Lung cancer	Community	Convenience	2 patients, 6 care-givers, 5 HCPs	Not stated	Not stated	Descriptive (constant comparison technique)	To identify common issues and to explore the needs and experiences of people with lung cancer, their carers and service providers
Lehto #283	2014	USA	Focus groups	Lung cancer	Community hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	11 patients	51-79	5M, 6F	Descriptive (thematic analysis)	To describe the lung cancer experience in relation to perceived stigmatization, smoking behaviours and illness causes

Lowe #570	2011	UK	Serial interviews	Lung cancer	Cancer centre	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	17 patients, 15 care- givers	Patient s = 48- 93. Care- givers = 40-81	Patient s = 12M, 5F. Care- givers = 5M, 10F	Theory informed (Interpretative Phenomenologic al Analysis)	To explore factors that influence patient distress within the lung cancer population
Lowson #571	2013	UK	Interviews	Heart failure, lung cancer	Acute hospital and communi- ty	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	27 patients (14 living with lung, 13 heart failure)	69-89	13M, 14F	Descriptive (framework approach, thematic analysis)	To explore the meanings of family caring for care recipients
Maguire #576	2014	UK	Interviews	Lung cancer	Acute hospital	Purposive	10 patients	47-80	4M, 6F	Theory informed (Interpretative Phenomenologic al Analysis)	To explore the lived experience of multiple concurrent symptoms in people with lung cancer
McCarthy #587	2009	Ireland	Interviews	Lung cancer	Acute hospital	Purposive	6 patients	53-74	2M, 4W	Theory informed (Interpretative Phenomenologic al Analysis)	To explore patients' experiences of living with NSCLC
Missel #597	2015	Denmark	Interviews	Lung cancer	Acute hospital	Criteria sampling approach (to select cases of predetermined criteria of importance)	19 patients	42-79	7M, 12F	Theory informed (Ricoeur's theory of interpretation)	To investigate how the diagnosis affects the daily lives of patients with operable lung cancer
Molassiotis #598	2011	UK	Serial interviews	Lung cancer	Cancer centre	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	17 patients, 15 care- givers	Patient s = 48- 93. Care- givers = 40-81	Patient s = 12M, 5F. Care- givers = 5M, 10F	Theory informed (Interpretative Phenomenologic al Analysis)	To explore lung cancer patients experiences of symptom clusters

Mosher #604	2015	USA	Interviews	Lung cancer	Cancer centre	Purposive	21 patients, 21 care-givers	Patient s = 39-80. Care-givers = 38-78	Patient s = 10M, 11F. Care-givers = 6M, 15F	Descriptive (thematic analysis)	To identify strategies for coping with various physical and psychological symptoms among advanced symptomatic lung cancer patients and their primary family care-givers
Petri #758	2015	Denmark	Interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	3 patients	65-72	2M, 1F	Theory informed (descriptive phenomenology)	To explore and describe the essential meaning of lived experiences of everyday life during curative radiotherapy in patients with NSCLC
Pollock #760	2008	UK	Serial interviews	Lung cancer and head & neck	Acute hospital	Patients screened against eligibility criteria. Those eligible, who wished to participate, included. Family members nominated by patients.	27 patients (15 living with lung, 12 H&N). 20 family members	Patient s = 41 - 85. Family members not stated	Patient s = 23M, 8F	Descriptive (thematic analysis)	To investigate service users' experiences of information delivery after a diagnosis of cancer
Powell #763	2015	UK	Interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	15 patients	58-87	5F, 10M	Descriptive (framework approach)	To explore patients' attitudes to the risks associated with lung cancer surgery
Robinson #777	2011	Canada	Interviews	Lung cancer	Community	Participants screened against eligibility criteria. Family members nominated by patients.	9 patients, 9 family members	Not stated	Not stated	Descriptive (constant comparison technique)	To explore the applicability and usefulness of an advanced care planning (ACP) intervention and examine the ACP process

Salander #786	2014	Sweden	Serial interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria and consecutively included.	15 patients	56-85	4M, 11F	Descriptive (constant comparison technique)	To understand how patients with lung cancer reflect upon their life situation after diagnosis and treatment
Sandeman #789	2011	UK	Interviews	Lung cancer	Acute hospital	Purposive	10 patients	46-82	4M, 6W	Descriptive (framework approach)	To explore the experiences of lung cancer patients attending routine follow up
Sjolander #931	2008	Sweden	Interviews	Lung cancer	Acute hospital	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	10 patients	47-88	8M, 2F	Descriptive (constant comparison technique)	To identify and describe the impact that social support and a social network has for patients with lung cancer
Steinvall #938	2011	Sweden	Interviews	Lung cancer	Acute hospital	Purposive	11 family members	56-73	7M, 4F	Theory informed (phenomenological-hermeneutic approach)	To identify and describe the experiences of quality of life/life situation among those who were next of kin to persons with inoperable lung cancer
Stone #941	2012	USA	Interviews	Lung cancer	Community	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	35 family members	36-72	6M, 29F	Descriptive (constant comparison technique)	To investigate communication and care in the context of lung cancer
Thornton #948	2011	UK	Interviews	Lung cancer	Cancer centre	Participants screened against eligibility criteria. Those eligible, who wished to participate, included.	5 patients	39-67	4M, 1F	Descriptive (thematic content analysis)	To explore the factors that influence patients' choice of treatment during the oncologist-patient consultation

Treloar #957	2009	Australia	Focus groups	Lung cancer	Acute hospitals	Participants screened against eligibility criteria. Recruitment continued until no new themes emerged.	22 patients, 13 care-givers	Patient s = 37-83. Care-givers = 39-75	Patient s 17M, 5 F. Care-givers = 1M, 12F	Descriptive (thematic analysis)	To identify the needs of people with NSCLC and their carers in relation to quality of life issues
Wickersham #975	2014	USA	Interviews	Lung cancer	Cancer centre	Purposive	13 patients	52-83	5M, 8F	Theory building (grounded theory)	To explore the process of medication-taking for NSCLC patients receiving oral epidermal growth factor receptor inhibitors